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LIVING WITH AIDS:
PART II

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Living with AIDS: Part II

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Preface to "Living with AIDS: Part II"

"LIVING WITH AIDS"—the phrase is sufficiently ambiguous to admit of many meanings. Yet, as was explained in the first of these two *Dædalus* issues on AIDS, the words are intended to convey a very specific message. If, as most informed men and women now believe, AIDS is a new infectious disease for which a medical cure is almost certainly not imminent, and if the ravages of this malady are likely to grow, continuing for a very long time, it is imperative that efforts be made to learn how to live with the deadly consequences of the infectious human immunodeficiency virus. Few societies are likely to remain immune to it. Many will confront political, social, moral, and economic dilemmas of considerable complexity and will have to consider types of institutional innovation and invention that have not figured to date.

AIDS has created a new agenda of public health concerns throughout the world, and perhaps nowhere more conspicuously than in the United States, which remains today one of the two epicenters of the disease. However unwilling certain individuals and groups both in this country and abroad have been to acknowledge the seriousness of the situation, finding any number of excuses for their inattention and lack of concern, the medical consequences of large-scale and continuing HIV infection pose problems that cannot be evaded. Whatever the mass media may report, the problem is not simply to express a willingness to care for those already infected who show the visible signs of their illness. One purpose of this *Dædalus* inquiry is to emphasize the need to mobilize the intellectual and material resources

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to study the disease, to look for a cure for it, or, failing that, to develop drug and other therapies calculated to extend life and reduce suffering. Another purpose is to acknowledge how difficult it may be to control the spread of the virus to individuals not now infected.

Since the difficulties of controlling or modifying human behavior, particularly in respect to sexual activity, where the resistances to change are so numerous and substantial, it is not enough to argue that greater public education efforts must be made. This, in effect, is a truism. When it comes to determining what specific educational efforts should be made and how they can be directed to influence individuals, often marginal and deprived, who are not easily reached by even the most imaginative educational campaigns, the real complexity of the problem begins to become apparent. With AIDS, even the matter of education becomes a contentious subject on which reasonable men and women will disagree.

At a time when the world is much preoccupied with the hazards of drug addiction, when whole societies have become dependent on income generated by illicit traffic in addictive substances, when police and other surveillance methods are clearly not sufficient to arrest the national and international traffic that continues to grow, and when saying no to drugs is uncommon among millions of willing consumers, AIDS is simply one more grave by-product of IV drug use, more deadly, certainly, but not thereby rendered more controllable by that grim fact alone. How the United States, with its vast material and intellectual resources, and other parts of the world, also infected but less obviously advantaged, choose to cope with AIDS, what policies and programs they adopt, given the nature of the political climates that now prevail, are matters all too rarely addressed. It is easier to see the issues in stark and simple terms, with right and wrong seeming to be self-evident.

For those who read this *Dædalus* issue, who consult also the one that preceded it, one conclusion is certain: we do not know how to cure AIDS, though substantial efforts are being made to discover the scientific and medical principles that may one day provide that result; meanwhile, the search for a therapy to convert the condition to a treatable chronic malady continues. There is little reason to be sanguine about an early resolution of the first problem; there is more hope for the second. In the interim, and perhaps for many years, the risks of new infection are considerable; given these hazards, we must

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make a deliberate effort to consider a whole array of problems in the United States and elsewhere that the continuing spread of the virus creates. Many are today averting their eyes from any number of social and political conditions described and analyzed in this *Dædalus* study. AIDS is a quite different phenomenon in various parts of the world, afflicting men, women, and children in very different proportions in societies that are substantially dissimilar. Ethical and moral issues, which have little to do with guilt or innocence, cannot be set aside. Until certain of the more hidden features explaining public attitudes and individual fears are recognized and acknowledged, with greater willingness to deal with sensitive issues of stigma and suffering, there is a hazard that some will seek to make AIDS one more infectious disease which, like any number of others, waits for the discovery of a "magic bullet." It does not help very much to think of AIDS as mostly a health-care problem, of concern primarily to physicians, nurses, and hospital administrators.

There is no denigration of the importance of any of these professionals in asserting that many other players need also to be engaged. In a democratic society, with such an issue, the shaping of public opinion is absolutely critical. Otherwise, the true dimensions of the crisis are lost in a welter of well-meaning verbiage. Questions that touch on issues of justice and law, economic and social organization, international cooperation and national pride, that reflect political interests and ideological differences as well as religious and secular convictions, need to be seen as relevant. To argue this is not to deny the primacy of certain of the scientific, medical, and public health aspects of the AIDS problem, which engage the attention of many who are gifted and committed, all too aware of how great the affliction is in certain parts of the world, not least in a number of cities in the United States. Still, AIDS is more than a health problem. It touches the society in ways that smallpox and cholera never did, that polio and other such infectious diseases could not.

Because of this, many see the AIDS crisis as providing an additional incentive for a more deliberate and detailed study of a great range of human problems touching on sexuality, drug abuse, and public health issues in the world of the poor, wherever they happen to be situated. It is not apparent that such grandiose objectives are today being realized. However much certain parts of the scientific and medical communities have been stimulated by the new, dangerous,

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and unanticipated health crisis created by AIDS, many humanists and social scientists concerned with public policy issues are still too little involved.

If, indeed, the disease can be used to throw light on characteristic features of contemporary society, revealing how resources are used, what material, moral, and intellectual constraints, often unmentioned, contribute to the formulation of policy, some benefits may be realized. While it may seem inhumane to suggest that the tragedy of AIDS be used to explore certain major problems of contemporary society, learning how delicate and difficult issues are both perceived and managed, such, in fact, can be one of the more useful results of a study of what is, incontestably, a terrible international scourge.

Again, as in the earlier *Dædalus* issue, I repeat my thanks to the John D. and Catherine T. MacArthur Foundation, to the Program in Science, Technology, and Society of the Massachusetts Institute of Technology, and to the American Foundation for AIDS Research for providing the financial support that made this study possible. I am grateful to all for providing the help that launched this study, that carried it forward to publication. This issue, like the first one, is dedicated to the memory of Dr. Robert Morison, longtime Fellow of the American Academy of Arts and Sciences and member of the Board of Editors of *Dædalus*, who helped the Academy and its journal over many decades in many ways. It is a great sadness that one of our authors, Dr. Norman Zinberg, died while this issue was in press. He contributed a great deal to our discussions. In recalling what he did, I would thank all those others, listed as members of the Advisory Board, who were so generous with their time and counsel. The two *Dædalus* issues owe much to their efforts, to their recommendations of why we should take a road not already much traveled, and why a certain candor was imperative.

S.R.G.

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Kenneth Keniston

Introduction to the Issue

AT THE FIRST PLANNING MEETING for this issue, an eminent microbiologist began the proceedings by commenting that "the first thing to understand about AIDS is that it is a biomedical problem." There were nods of agreement from the assembled group, mostly scientists and physicians.

But as the meeting went on, the conceptual waters became muddied. It was soon said that AIDS is a public health problem, a political problem, a psychological problem, an educational problem, and a litmus paper for other problems in our society. AIDS was called a problem that must be understood in historical context, a problem in public attitudes, and a moral problem (at least as construed by certain segments of the American population). AIDS was also seen as a "disease of civilization" and a problem of relationship between the developed and the less developed world, between whites and non-whites, and between the straight population and the gay population. Finally, since our biomedical friends advised that no solution was likely for the foreseeable future, perhaps AIDS was not really a problem at all, especially if defining something as a problem presupposes that there is a solution.

THE SOCIAL CONSTRUCTION OF AIDS

This discussion led some of us, historians or social scientists, to reflect on the "social construction" of AIDS. It was early apparent that to

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define AIDS as, for example, a biomedical problem was to make both an intellectual claim and an implicit claim on material resources. Calling AIDS a biomedical problem stakes out the turf. If the claim is persuasive, it channels resources—money, grants, hospitals, publications—to biomedical workers as those who are to deal with the problem. Furthermore, such claims tend to exclude other claims: research, publications, money, people, and programs allocated to solve a problem defined one way are not available to solve the problem defined in other ways. I do not mean that proclaiming AIDS a biomedical problem is either incorrect or consciously self-serving but simply that accepting this definition channels resources, no doubt appropriately, toward biomedical research aimed at biomedical solutions.

Definitional claims invite counterclaims. Here is a competing definition of AIDS from a group of social scientists:

> The spread of HIV infection and, consequently, AIDS is the product of human behaviors enacted in social contexts. Both the behaviors and the circumstances in which they occur are conditioned and shaped by culture and larger social structures. The epidemic is thus as much a social and a behavioral phenomenon as it is a biological one.[1]

In discussing AIDS, then, we are involved in what one fellow social scientist called "heavy-duty social construction." AIDS is, after all, a new condition, identified only in 1981. It arrived in our midst without a traditional set of meanings. Indeed, the first names assigned to it—"gay plague" and "gay-related immunodeficiency syndrome"—turned out to be profoundly misleading and harmful. One way to understand the debates about AIDS is to see them as struggles to define the meaning of AIDS in terms of preexisting concepts, paradigms, theoretical frameworks, and metaphors.[2]

AIDS is socially constructed in two ways. First, it is socially constructed in the sense that any disease is, be it typhoid fever, bubonic plague, chicken pox, Legionnaire's disease, syphilis, or influenza. That is, we assign a meaning to the condition, including all that is implied by calling it a disease, in a broader framework of traditional meanings, appealing metaphors, and convincing theories.

But second, the very disease of AIDS itself is socially constructed. Referring to the symptoms of HIV in distinct populations, Lincoln Chen, professor of international health at Harvard University, put it

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well: "Same virus, different disease."[3] Much of the symptomatology of AIDS is caused by opportunistic infections to which the body is made vulnerable by the suppression of the immune system. As a result, the nature of these symptoms differs on average from population to population and from region to region according to the prevalence of local infections. No one is yet sure of the "cofactors" that determine the symptomatology and progression of the HIV virus, but it is clear that the symptoms of AIDS in, let us say, Kinshasa, Newark, and San Francisco differ to the point that, were it not known that a common retrovirus lies behind the vulnerability of the organism in all cases, one might well suspect that quite different diseases—and causal agents—are involved. Not only is the *meaning* of AIDS socially constructed, but the *symptoms* grow out of personal, ecological, social, cultural, and historical contexts.

If we misdefine AIDS, we risk shaping ineffectual or counterproductive policies. To define AIDS as "God's judgment on a society that does not live by the rules," as does Rev. Jerry Falwell, directs us toward blame, penitence, and moral reform as the only effective responses to this affliction. To see AIDS as an entirely biomedical problem deflects us from promoting behavior changes that could limit its transmission. To view it as a problem likely to be solved in the near future undermines the resolve needed to live with AIDS for decades and generations. We must therefore weigh competing social constructions of AIDS against what we know about this condition and against whether they promote policies that can reduce the damage HIV causes.

WHAT WE KNOW ABOUT AIDS

To evaluate prevailing images of AIDS, we must start by asking what has been learned about this condition in the eight years since it was first recognized.[4]

First, as for transmission, we know that the human immunodeficiency virus (HIV) is transmitted by the entry of a retrovirus in semen, vaginal secretions, or blood from an HIV-infected person into the body of a non-HIV-infected person. This is the only known mode of transmission.

The most "efficient" mode of transmission is blood transfusion: in close to 100 percent of cases, transfusion will transmit the virus when

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the donor has overt AIDS symptoms or is close to developing them. The sharing of needles by intravenous drug users is also relatively efficient, although no one knows the precise factors that determine the risk of infection. Transmission from pregnant mother to unborn infant appears to be 20 to 50 percent efficient, with higher efficiency if the mother has overt symptoms of AIDS. Sexual intercourse is a relatively inefficient means of transmission, although it is by far the most common. For example, the regular sexual partners of transfusion-related AIDS cases show relatively low HIV-positive rates in some studies. Lesions, infections, or sexual practices that encourage the entry of semen or vaginal secretions into the bloodstream of the noninfected partner may increase the risk of sexual transmission.[5] Finally, accidental "needle stick" injuries of AIDS researchers and health workers are an exceedingly rare form of transmission. There are no other known modes of transmission: not insects, not air, not water. AIDS is infectious but not contagious; despite its virulence and its prevalence, it is difficult to transmit.

Second, as for the course of this condition, we know that HIV infections are largely asymptomatic for a period of, on average, seven to eleven years (considerably fewer in newborn infants).[6] People are generally unaware that they are infected for many years, unless of course they are tested for antibodies. No one has yet identified the "cofactors" that may determine the onset of overt symptoms. But all the evidence available is consistent with the view that almost everyone who becomes HIV positive will eventually develop symptoms of AIDS.[7] Once symptoms develop, they evolve inexorably; despite antiviral treatment and excellent medical care, death usually occurs within two years. Even if opportunistic infections can be treated effectively, death ensues from the direct effects of the infection on the cells of the body, including the brain. Dying from AIDS is extraordinarily long, disfiguring, and agonizing.

Third, what do we know about the prevalence of AIDS? In the absence of precise epidemiological studies of seropositivity, which exist in no country in the world, all estimates of prevalence necessarily are rough. For the world, estimates run between 5 million and 10 million HIV-positive individuals; for the United States, between 945,000 and 1.4 million—that is, about 1 in 200 Americans.[8] Most of those affected are young adults between the ages of twenty and

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forty-five, with the exception of small groups of newborns and transfusion AIDS cases, who tend to be older.

There are three rather different national and regional patterns of seropositivity.[9] One is most characteristic of America, western Europe, and Australia, where gay men and intravenous (IV) drug users, along with their sexual partners, constitute the great majority of cases: these people are largely male. There is as yet no evidence of the large-scale spread of seropositivity to the heterosexual population in northern industrialized nations.[10] Another is the pattern in parts of Africa and the Caribbean, where the dominant mode of transmission is heterosexual, and where the HIV-positive are about equally distributed between the sexes. The third pattern is that of countries like Japan, China, India, and the Soviet Union, where AIDS is infrequent, and where isolated cases are said to be associated largely with sexual contact with HIV-positive foreigners.

In some subpopulations, prevalence is extraordinarily high: for example, among some hemophiliacs who have received multiple transfusions of clotting factor derived from many donors, prevalence approaches 90 percent; among some gay populations in major American cities, over 50 percent; among young adults in some African cities, perhaps as high as 20 percent.[11]

Finally, what do we know about the prospects for cure, prevention, or treatment? Clearly, any statement here is predictive and could be proven wrong. But there is a large consensus among those working on the biomedical aspects of AIDS about the long-term picture. First, there is at present no cure for AIDS.[12] Although the physical and psychological suffering of those who have this condition can be alleviated by devoted and careful medical care, eventual suffering and death cannot be prevented. Second, once symptoms of AIDS appear, zidovudine (AZT), an antiviral agent, can delay but not prevent death. Researchers working on antiviral agents to treat AIDS are hopeful that other less toxic and more effective agents will be found in years ahead. AZT or other agents might also delay the onset of symptoms, but this relationship is not established. Clinical trials of antiviral agents necessarily take many years, given the long period that usually separates infection from overt symptoms of disease. Whether chemoprophylactic agents as yet to be found could also prevent the transmission of the retrovirus (as opposed to delaying the development of symptoms) is an open question.[13]

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As for prevention through immunization, the prospects in the next decade or so are also viewed as poor by those working on vaccines.[14] The reasons for pessimism spring from the complex and protean nature of the retrovirus, and with the mode of its infectivity, which renders ineffective or paradoxical most of the known techniques for combating or preventing viral conditions. Some researchers believe that the complexity and mutability of HIV means that, like influenza, it can never be prevented by a single vaccine. The likelihood of a penicillin-like cure or a Salk vaccine for AIDS is for the present small.

THE DREAM OF ELIMINATING AIDS

The goal of current efforts to "fight" AIDS is to overcome, prevent, or eradicate this condition. The implication of most of the metaphors and theories by which we seek to understand AIDS is that this is a reasonable goal attainable in a matter of years. Since we are bent on eliminating AIDS, we rarely ask what it would mean to have to live with this condition. It is therefore important to ask whether the goal of eliminating AIDS is realistic.

Our first and best hope is biomedical, and it is into this area that most resources are now being poured. What might the biomedical conquest of AIDS mean? What would it require?

Smallpox is the only example in world history of a disease that has been completely eliminated by medical means. But an inexpensive, effective, long-lasting, safe vaccine, has been available for about two centuries. Smallpox is a highly contagious disease that manifests itself in outbreaks concentrated in specific populations: it is all too clear who suffers from smallpox and who does not. As a result, unaffected members of populations at risk of contagion can be immediately identified and vaccinated. Vaccination against smallpox can be given soon after birth and usually remains effective throughout a lifetime.

AIDS is very different. The seropositivity of those who are capable of transmitting AIDS is invisible during most of the long course of this condition. In the absence of testing, there is no way of knowing who is and who is not HIV positive until actual symptoms appear, which is usually many years after infection, a period when transmission of AIDS is possible. Hence, there is no feasible way of isolating AIDS carriers, nor any way of identifying those at risk of infection. And, as we have said, there is no AIDS equivalent of the smallpox

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vaccine. If a vaccine should be created, it is unlikely to be as cheap, safe, effective, long-lasting, or universally available as smallpox vaccine. Smallpox is therefore a misleading model.

What is the prospect of discovering a cure for AIDS—a magic bullet, a simple, effective, inexpensive medication that would eliminate HIV from the body and restore the individual to a prior condition of seronegativity without lasting damage from the illness? Medical researchers consider the likelihood slim in the next decade or so.

Even if we had something that would be as effective as penicillin is against syphilis, the chances of completely eradicating AIDS would be small. HIV has few specific symptoms for five, ten, or perhaps fifteen years after the date of infection. The early signs of syphilis and of many other sexually transmitted diseases are absent. AIDS could only be cured, therefore, under two conditions: when symptoms have already developed or when individuals have taken the AIDS test and know themselves to be seropositive. In the first case, a cure would not prevent the transmission of HIV, since seropositive individuals would have had many years to transmit the virus before symptoms became evident. This leaves the second case: eliminating AIDS would require the mandatory testing of the 6 billion and more people in the world, coupled with immediate, mandatory treatment of all who were HIV positive. Even if the astronomical costs of such an effort could be borne, the logistics of achieving mandatory worldwide testing and treatment seem insuperably difficult.

Our experience with syphilis and other sexually transmitted diseases further dims our hope of eradicating AIDS. Syphilis can usually be identified early. Relatively effective, cheap, nontoxic cures are available, and even resistant strains yield to new antibiotics. Despite the ease with which syphilis can be recognized and treated, and despite case finding and tracing of sexual partners, syphilis persists; we are probably best advised to consider the possibility of contracting syphilis to be a risk of human existence for all foreseeable futures. Even if a cheap, effective, and safe cure for AIDS were found, we should not expect this less visible and more intractable disease to be eradicated.

Finally, what about the prospects for treatment? The recent report that AZT may lose its effectiveness over time is discouraging for those who hope for an early antiviral antidote to AIDS. But let us assume

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that antiviral agents that could indefinitely defer the onset of symptoms were discovered. Could we then anticipate the eradication of AIDS?

Probably not. Once again, early HIV infections are asymptomatic and can be transmitted during many years of latency. Barring a worldwide program of mandatory AIDS testing, coupled with mandatory, effective, and lifelong chemoprophylactic treatment of all those who tested positive, we could not reasonably anticipate the elimination of AIDS.

Of course, a chemoprophylactic agent that not only deferred the onset of symptoms but prevented the transmission of AIDS might be discovered. Under these circumstances, if all seropositive individuals were identified and treated indefinitely, AIDS could eventually be eliminated. All those who are currently seropositive would eventually die, but there would be no new cases. Yet the practical difficulties of achieving this goal seem insurmountable. The costs of lifelong treatment with chemoprophylactic agents, even if such treatment could be medically provided and coercively enforced, would be prohibitive. The present annual cost of AZT treatment—$8,000 per patient—makes improbable the prospect of treating 5 million to 10 million people, many of them in the poorest nations of the world.

Thus, even if the most optimistic forecasts of medical progress on any or all fronts proved correct, the likelihood of completely eradicating AIDS by biomedical means would still be small. The central problem is that almost a decade usually elapses between infection with HIV and the development of overt symptoms, during which time HIV can be transmitted unwittingly by anyone who is seropositive.

Pessimism with regard to the biomedical eradication of AIDS should not, of course, lessen the intensity of the search for efficacious biomedical agents. Immunization, curative treatment, effective antiviral agents, or chemoprophylaxis would make an enormous difference. In combination, they would over time reduce the prevalence and transmission of HIV and the suffering and death that go with AIDS. But it is hard to see how they could eliminate this affliction.

PUBLIC HEALTH AND BEHAVIOR CHANGE

Since even the most serendipitous biomedical advances are not likely to eliminate AIDS, what can be expected from other measures? After

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all, the near elimination of most epidemic diseases in the Western world in the last century resulted not only from biomedical achievements but, antedating them and perhaps more effective in saving lives, from public health measures that required no startling medical advances or drastic changes in human behavior. How effective can public health measures be in eliminating or controlling AIDS?

If public health measures are defined as those that require little or no individual behavior change, the answer must again be pessimistic. In only one area, transfusion AIDS, can such public health interventions make a difference. In industrialized nations, the routine HIV testing of transfusion blood has reduced this means of transmission dramatically, though not entirely. In developing nations, the situation is more complex, with testing of donor blood for HIV still absent or incomplete, and with syringes frequently reused in medical settings. Especially in central Africa, where the problem is severe, programs of donor blood testing are slowly being developed and efforts to prevent medical reuse of syringes are under way. The combined efforts of the African nations and of the World Health Organization will not solve this problem in the immediate future but could do so within a decade.

Apart from monitoring medical transfusions and medical syringe reuse, however, there is little that public health authorities can do. Unfortunately, medical transfusion and syringe transmission of AIDS is but a tiny part of the problem. The most prevalent modes of transmission are sexual intercourse and intravenous drug use. In these two areas of human behavior, public health measures that do not require change in individual behavior have little relevance, and we move to the realm of education. How likely is it that education can alter behavior so as to eliminate or at least vastly reduce the incidence of AIDS?

In principle, it is of course easy to avoid contracting AIDS. At the extreme, obedience to two simple maxims—"No sex" and "No IV drugs"—would eliminate virtually all future transmission of AIDS. More realistically, obeying the slogans "Use condoms" and "Sterilize needles" would radically reduce the risks of infection. Social scientists who argue that AIDS is above all a behavioral problem rest their claims on precisely this fact. But the unfortunate further fact is that AIDS, although not easy to transmit, is transmitted by the most difficult of all behaviors to change by educational means: sexual

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behavior and addictive drug use. The reasons for these difficulties merit analysis.

Every society seeks to control sexual behavior, regulating formally and informally when, with whom, and how sexual relations occur. But by the same token, every society fails to control sexual behavior completely, and modern societies fail very notably. The best example is the failure of educational campaigns intended to prevent unwanted pregnancies. Despite the availability of inexpensive and effective modes of contraception, many of them less onerous than the use of condoms, and despite educational efforts, unwanted pregnancies continue and even increase in number in industrialized nations like our own. Educational attempts to limit the number of sexual partners, another critical risk factor in the transmission of AIDS, also seem relatively ineffective. History thus gives little ground for optimism about the efficacy of campaigns to eliminate AIDS by encouraging abstinence, monogamy, or "safer sex."

The evidence about the specific impact of AIDS on sexual practices is not encouraging. Often cited as causes for optimism are changes in sexual behavior—specifically, the adoption of safer sex practices—among gay men in cities like San Francisco.[15] It should be noted, however, that this evidence comes from groups where seropositivity has reached about 50 percent. On a worldwide scale, such a pattern would require 3 billion actual or future AIDS cases before behavior change occurred—hardly a comforting thought. Furthermore, other data contradict this "optimistic" evidence about changes in the behavior of gay men in America. They point to a recent increase in the general population in the incidence of sexually transmitted diseases like syphilis, whose transmission should be reduced by the widespread adoption of safer sex practices.

Complicating efforts to modify sexual behavior are three factors specifically related to AIDS: youth, sexual activity, and uprootedness. Men and women who are HIV positive are characteristically young and sexually active by virtue of that fact alone. Besides, within the youthful age group, people with AIDS are unusually active sexually and have an unusually large number of sexual partners. Both factors suggest that their sexual behavior is driven by needs other than a careful weighing of the risks of transmitting AIDS. And in both the industrialized nations and the developing nations, AIDS is most common in uprooted, mobile, anomic urban populations of young

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adults. Such men and women, disconnected from traditional social and cultural networks, are relatively unaffected by formal or informal admonitions to modify their sexual behavior. In other words, seropositive individuals tend to be especially impervious to educational campaigns intended to persuade them to change their sexual practices. Attempts to modify sexual behavior, while clearly worth pursuing, are likely to be extraordinarily difficult: time-consuming, resource-consuming, and discouraging in their short-term results.

The other common mode of transmission is through the use of unsterile needles in intravenous drug use, in particular, through needle sharing by users of heroin, cocaine, and other injectable drugs. Here, too, optimism about the efficacy of education would be unwarranted. Despite generations of warnings, educational campaigns, school programs, and the like, intravenous drug use in the industrialized nations appears to be increasing rather than decreasing. Since a disproportionate number of IV drug users are poor, nonwhite, and little educated, they are particularly resistant to most conventional educational campaigns. The fact that such people are usually addicted to the drugs they inject leads them to give the acquisition and use of drugs priority over virtually all other desires, including the desire to avoid endangering one's life or that of one's friends. Educational programs "targeted" at IV drug users are therefore likely to be ineffective or slow to show results.

In brief, efforts to change individual behavior so as to prevent or limit the spread of AIDS should have high priority. In the short run, they probably constitute our best hope for curtailing the transmission of AIDS. But there is no reason to believe that the AIDS problem will make changing sexual behavior or curtailing IV drug use much easier than it has been in the past.

AIDS, MORALITY, AND LIBERTY

The likelihood of eliminating AIDS also depends on the priority we assign this goal. While everyone would agree that eradicating AIDS is desirable, we all have other goals that may override and interfere with AIDS elimination as an objective.

As a thought experiment, imagine AIDS as if it were a disease that selectively affected white middle-class girls between the ages of two and fifteen. Associated for unknown reasons with youth, femaleness,

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parental income, and citizenship in an industrialized nation, AIDS would spread slowly outward from this first "risk group" but always remain concentrated in the young, privileged, female populations of industrialized states. If these had been the circumstances, would the political response to AIDS have been the same as it has been in actuality?

The answer is almost certainly no. It is hard to imagine that President Reagan would have waited to discuss the disease until a million prosperous young American girls were affected.[16] A public clamor for a solution to AIDS would surely have come sooner. Nor is it possible that hospital facilities for children with the symptoms of AIDS would be so inadequate. Is it imaginable that fundamentalist preachers would have seen AIDS as a divine punishment for moral transgressions? Or that major journals would have contrasted "innocent victims" (transfusion cases) with the great majority of those thought in some way not believed to be "innocent"? Is it conceivable that senators, congressmen, presidents, and other elected and appointed officials would so often have shied away from AIDS entirely, or implicitly blamed those with AIDS by expecting them to do something about their own condition?

This thought experiment underlines the importance of political priorities. To be sure, it is not clear that a different political response would have drastically altered the spread of AIDS in the last decade. But despite the recent mobilization of resources to focus on biomedical and behavioral aspects of AIDS, it is clear that this response has been slowed by the stigmatized and disadvantaged status of those affected with AIDS.

Approximately 80 percent of those who are HIV positive in the world are people of color, and most of the rest are IV drug users, poor and/or gay. What all these groups have in common is a low claim on resources. The majority of those who are HIV positive live in developing nations of the world like Zaire, Haiti, and Uganda, and the first problem of such nations is endemic poverty. In countries where per capita health expenditures average less than $25 per year, how can an effective campaign against AIDS be organized? Furthermore, as the World Health Organization has rightly insisted, AIDS is not the number one health problem in such nations.[17] Conditions like dysentery, tuberculosis, and malaria will for the foreseeable future take a far greater and more easily preventable toll. The

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problem is that developing nations have few resources of any kind, much less the resources necessary for a concerted "attack" on AIDS (even if an effective attack were possible). Equally important, their claim on international resources has a low priority, and the possibility of massive transfers of people, medications, and other resources from the developed world to these countries is tragically small.

A similarly low claim on resources characterizes the groups where AIDS is most common in the developed countries. To be sure, the gay community has organized itself into an effective lobby for AIDS research and education in America and western Europe. But gays remain a stigmatized group, and few politicians have the courage to put the claims of homosexuals on a par with those of other citizens. IV drug users are perhaps the most despised of all groups in America. They have no political clout whatsoever. In general, as AIDS moves into poor, black, or Hispanic neighborhoods in American central cities, the ability of its sufferers to command political attention and resources diminishes.[18]

The general claims against which AIDS-prevention efforts must compete most vigorously are those of "morality" and "freedom."[19] Morality enters the argument because AIDS is largely transmitted through behavior deemed immoral: the use of illegal drugs or the practice of extramarital and/or homosexual sex. To strict moralists, the only proper response to AIDS is therefore no drugs and no extramarital and/or homosexual sex. But any effective AIDS-prevention strategy must aim at making these "immoral" behaviors safer—by, for example, providing sterile needles and making condoms widely available. Especially in the United States, the desire not to condone "immorality" has effectively prevented the provision of sterile needles and has impeded efforts to provide clear, frank education about safer sex.

On the other hand, AIDS prevention runs afoul of many civil libertarian values. Gays opposed the closing of bathhouses because this seemed to threaten their fragile sexual freedom.[20] Proposals for mandatory testing, mandatory treatment, or mandatory partner tracing raise fears of the violation of the freedom and rights of those who have, or might have, AIDS. So acute are these fears that in some states the legal requirements for reporting and tracing the sexual partners of AIDS cases are far less stringent than those that apply to other less lethal sexually transmitted diseases.[21]

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AIDS-prevention efforts walk a tightrope between morality and freedom, but of course both these values are important. IV drug transmission of AIDS, for example, could be almost entirely eliminated by making freely available nonreusable syringes of heroin, cocaine, and other currently illegal injectable drugs. But only a few would advocate so drastic a legalization of addictive drugs. Similarly, a mandatory national AIDS-testing program, coupled with the indefinite quarantine of all the million or so seropositives and the permanent sealing of all American borders, might reduce the chances of Americans contracting AIDS. But who would wish to pay the price? And African nations are surely right in insisting that AIDS should not diminish the priority assigned to eliminating other diseases; Africans are understandably cynical when AIDS, which affects industrialized nations, brings to their continent a flood of American and European experts who were not attracted by dysentery and malaria.

What is clear, however, is that the priority of any attack on AIDS, be it biomedical or behavioral, is determined within a network of other competing priorities. This network is intensely political. The relatively stigmatized, disadvantaged, and resourceless nature of AIDS-afflicted populations has slowed the channeling of resources to the study and control of AIDS. Since AIDS is likely to remain prevalent in stigmatized and disadvantaged groups, other priorities will probably continue to have greater weight than AIDS. On this ground, too, then, optimism about eliminating AIDS is unwarranted.

METAPHORS AND THEORIES OF AIDS

If the prospects of eradicating AIDS are almost nil, and if even the more modest goal of controlling AIDS is beyond our immediate reach, how should this situation affect the meanings we assign to this lethal condition? Do our current metaphors and theories mislead us? How should we socially construct AIDS?

The metaphor most used to understand AIDS is that of war. We speak of our battle with AIDS and vow to fight it. A war, as author Susan Sontag notes,[22] involves an enemy, soldiers on both sides, weapons, a struggle to win. As she does not note, it also suggests an outcome: the idea that the war will end in victory or defeat. Thus, the war metaphor, with its unstated hope that there will be a victory for

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our side, also prepares us poorly for the long-term consequences of AIDS. Wars eventually end. They do not get steadily worse or continue indefinitely. They are followed by a time of peace. We do not view them as something we must live with forever. But as I have suggested, this is unlikely to be the case with AIDS.

If in most of us, optimists, the war metaphor promotes fantasies of complete victory, in pessimists, it encourages the equally problematic image of unconditional defeat. To pessimists, the war is already lost: the incidence of AIDS will double every year until vast proportions of the world's population are affected. The medical-care system will be overwhelmed; health insurance will collapse; nations will be decimated; international trade will cease; production will plummet; and the vestigial uninfected population will barricade itself in armored enclaves to prevent infection.

This dark view, too, fails the test of plausibility: it assumes that no intervention or combination of interventions—medical, behavioral, social—will make a difference. It assumes that controlling AIDS will not receive the priority it deserves until it is too late and until only the most desperate measures are possible. By predicting total and inevitable defeat, it disarms us for the efforts necessary in the long run.

Another common metaphor is that of the AIDS crisis. A crisis is, of course, a turning point—the moment in a drama or in the course of a disease or a social problem when conditions peak, when something has to be done, and when, depending on what we do, the problem either subsides or leads to catastrophe.

This metaphor is also misleading. Of those who will be afflicted with the symptoms of AIDS, only a tiny percentage are now so affected. Every responsible forecast involves an increase in the number of symptomatic AIDS cases, with no clear crisis in sight. We do not know, for every individual who today dies of AIDS, how many individuals already have become HIV positive. But for the foreseeable future, there will be no turning of the tide, only a steadily worsening situation. If there is to be a turning point, it will be far in the future.

Another prevailing image of AIDS is that of epidemic, or more dramatically, of plague. As Professor Charles Rosenberg of the University of Pennsylvania has pointed out,[23] this metaphor is inviting and in some respects accurate. But we think of epidemics and plagues, like crises and wars, as mass afflictions that grow, crest,

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reach a peak, lay waste to a proportion of the population, and then subside or disappear. The problem, again, is that we have no idea when AIDS will crest, or indeed whether it will crest. The epidemic and plague metaphors thus also ill prepare us for the long-term prospects.

Of the many other social constructions of AIDS, I will comment only on the one we virtually all accept, namely the characterization of AIDS as a "disease" and its incorporation into a biomedical framework of understanding. Such a characterization would seem to be only commonsensical in a rational-scientific age. But had AIDS first appeared a thousand or even a hundred years ago, the disease construction, with its biomedical implications, would have been unimaginable. The plagues of the Middle Ages were seen as divine visitations and punishments or else as poisonings brought about by subversive pariah groups like the Jews. Illness in many societies today is seen as a consequence of witchcraft and sorcery, not of bacteria, viruses, or retroviruses. AIDS viewed as a disease is a characteristically modern construction.

But is it in any way misleading? Let me grant at the outset that the biomedical view of AIDS is, overall, the best single way of understanding it. It transforms the afflicted into patients, deserving of medical care regardless of their status, race, or previous behavior. It assigns special responsibility for AIDS to two benign groups: first, to doctors, nurses, and medical technicians, who are trained to deal with diseases in an affectively neutral, nonjudgmental, and life-preserving way; and second, to molecular biologists and medical researchers, who are taught to search out, master, and overcome the retrovirus scientifically identified as the root cause of this condition. For all the notable lapses of compassion, kindness, generosity, and equity in the treatment of those afflicted with AIDS, these lapses arise not so much from the medical model as from a failure to adopt it.

Nevertheless, we need to recognize the limitations of the disease model. To repeat, AIDS does not have uniform symptoms, but arises from a retrovirus that causes "different diseases" in different settings.[24] Unlike most diseases, AIDS has no symptoms during much of its course: HIV is unrecognizable except through medical tests and causes no immediate distress to anyone. With no vaccine and no cure, we can only delay or palliate some of the symptoms once they surface. The most optimistic medical prospect for the near future, far

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from involving prevention or cure, is that we will find a safe, effective antiviral agent to defer the onset of symptoms. Although clearly infectious, HIV thus differs from most other infectious diseases. AIDS is in some ways more like a chronic condition, such as diabetes (which is often latent but of course is noninfectious), than it is like most infectious diseases, such as viral pneumonia or measles. In other ways, AIDS resembles conditions like polio or Spanish influenza, characterized by an initial infection that may be followed by additional symptoms decades later.

Simply to characterize AIDS as a disease without further qualification is therefore misleading. AIDS is surely a disease in that scientists have identified an infectious agent (or agents) that produce its symptoms. But in other respects, AIDS is sui generis: in its initial invisibility to its victims, in its prolonged latency, in its protean symptomatology, in its apparently invariant virulence, in the cruelty of the processes by which it destroys. Furthermore, AIDS differs from other diseases in that its origins lie in a human lentivirus of a kind rarely identified and imperfectly understood. The disease model also misleads us to expect that AIDS will soon yield to another of the "magic bullets" or "wonder vaccines" that have made other infectious diseases so rare a cause of death in the industrial world.

And even if we agree to call AIDS a disease of a new and different kind, this definition must not monopolize its meaning. AIDS has behavioral and social roots as well as biomedical causes. For the moment, the only interventions that might limit its transmission are behavioral. These interventions, I have argued, are bound to be difficult and controversial since they aim at making safer a series of acts that many deem immoral. To call for safer nonmarital sex or safer IV drug use invites bitter political controversy, whereas to call for "more biomedical research" is politically advantageous. Nevertheless, if we really want to prevent a rising toll from AIDS, only a definition of this condition as also a behavioral problem can legitimize policies that might be effective in the coming years.

The greatest problem with an exclusively medical definition of AIDS, however, is that it may leave out the actual experience of this affliction. Like any characterization of a human woe as a disease, the medical definition links AIDS to the interpretive framework of modern biochemical science and to the rational-scientific world view of which biomedicine is an important part. This view is characterized

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by its detached and respectful attitude toward facts, its efforts at objectivity, and its interpretation of the givens of nature, including diseases, as data to be studied, explained, and reduced to more basic phenomena.

One of the virtues of science is precisely that it lays aside all judgments and feelings. It encourages us to perceive, study, and understand the facts of the world without passion or prejudice. By making AIDS a disease to be dispassionately analyzed and mastered by science, the biomedical definition therefore distances opprobrium, revulsion, and hatred from our reactions to this affliction. By defining those who suffer from AIDS as patients, the biomedical view lessens the temptation to treat people with AIDS as wrongdoers or sinners who deserve their fate. It replaces any propensity to rail ineffectively at AIDS with a dispassionate effort to master the intellectually challenging puzzle of this complex and little-understood condition.

At the same time, however, the affective neutrality of the biomedical worldview neglects—or more precisely renders largely irrelevant and therefore invisible—the horror of the affliction and the suffering of those afflicted. Yet in the daily experience of those who have AIDS, of those who love them, and of the biomedical professionals who treat them, horror, anguish, and a sense of tragedy are constant companions—along with courage, care and generosity. The danger of a too-wholehearted embrace of the disease construction of AIDS is that it affords little place for such feelings. While it discourages blame and hatred, it may also drive away acknowledgement of the pain, disfigurement, and despair of those who have AIDS and of their valiant confrontation with their condition.

To do justice to these aspects of this affliction, we must perhaps search for interpretations in the vocabulary of generous religious worldviews, largely eclipsed by modern science. And even if that vocabulary and the faith that sustained it are largely lost to those of us who share the rational-scientific view of the world, we should recall that in AIDS, the phenomena to which they refer are still present—even though rendered invisible by the lens of AIDS viewed solely as a "biomedical problem."

THE FUTURE OF AIDS

I have argued that the only safe forecast is that AIDS will be with us for a long time, and that metaphors and conceptual frameworks that

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lead us to expect anything else mislead us. Can this general prognosis be refined?

Consider the key question of how many people will actually suffer and die from AIDS. Of the 5 million to 10 million people worldwide who are now seropositive, only a small percentage have so far shown symptoms of AIDS, and an even smaller percentage have died. On the current assumption that virtually all those who are seropositive will eventually develop symptoms and die, and given the current estimate of a median of 9.8 years from infection to death, we can predict that half of those who contract AIDS in any given year will have died a decade later. The rate of HIV infection has almost certainly increased since 1980, so there will be a mounting number of AIDS deaths at least until the turn of the century, barring unexpected medical advances.[25]

What happens in the twenty-first century depends partly on the results of biomedical research. If by some miracle, the transmission of AIDS were suddenly to cease this year, AIDS deaths would crest around the turn of the century and decline slowly in the following decade until all HIV-positive people who were going to die had died. But if we accept the assumption that AIDS transmission is not declining—an assumption implicit in most discussions—then symptomatic AIDS cases and deaths will steadily increase, reflecting regularly increasing transmission rates a decade earlier. If, for example, AIDS transmission rates increase for ten more years, the number of AIDS deaths will be higher in the year 2010 than ever before. Any downturn in AIDS deaths could be expected only a decade after AIDS transmission rates had begun to decline.

The critical factor, then, is the transmission rate—whether on average seropositive individuals transmit seropositivity to more or less than one other person during their lifetimes. If the number averages less than one, AIDS deaths will begin to decline after about a ten-year lag; if it is exactly one, AIDS deaths will level off in ten years or so; if it is more than one, AIDS deaths will increase after a ten-year lag.[26]

It is of course to be hoped that such calculations will be thrown off by medical advances. A vaccine or a cure could reduce transmission rates and deaths. Effective antiviral treatments could increase the time between infection and death, perhaps enough that most HIV-positive men and women would die of causes other than AIDS. But unless

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treatment deferred symptoms indefinitely, it would only prolong the time before death, not reduce the eventual toll. Furthermore, any agent that simply doubled the life expectancy of seropositive individuals would—other things being equal—double the period during which they could transmit AIDS—thereby doubling the transmission rate.[27]

The future of AIDS thus depends on the rate at which it is transmitted, and the transmission rate in turn reflects three interacting factors: biomedical advances, behavior changes, and what can be thought of as the normal social ecology of transmission-related behavior. The last deserves brief explication.

Earlier I emphasized that AIDS is, among infectious diseases, one of the most difficult to transmit. One study points to the possibility that AIDS may be contained simply by the "ecology" of social relations in stable communities.[28] In 1976, researchers drew blood samples from the entire population of an isolated African town. Ten years later, blood samples were again drawn from all the inhabitants of the town. Both sets of blood samples were tested for HIV. At both times, the HIV rate was the same: eight-tenths of one percent. This suggests a transmission rate over a decade of exactly one: the ordinary patterns by which sexual relations are governed in that community were evidently adequate to limit the spread of AIDS.

An isolated African town differs of course from the major cities where AIDS is most prevalent. But this study nevertheless points to the AIDS-limiting potential of most natural communities. Throughout the world, IV drug use is abhorred by virtually every community; most communities and most individuals favor constancy of sexual partners over sexual relations with multiple partners. Since the chances of contracting AIDS in a single sexual encounter with an HIV-positive individual are low, these existing community norms serve to reduce AIDS transmission. In the end, they are probably the major factor that will limit the spread of AIDS.

But whatever the factors that may eventually reduce the present rate of increase in AIDS, we can confidently predict that in the year 2000, and probably in 2010, AIDS will be a more common cause of death than it is today. Thereafter we can only anticipate that AIDS, however controlled, will be unlikely to disappear: even at best, it is likely to become one of the many small but ineradicable risks of human existence.

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Metaphors and theories that fail to ready us to live with AIDS therefore serve us poorly. They inspire false hopes of the rapid "conquest" of this condition; conversely, they inspire paralyzing fears of imminent catastrophe. In either case, they disable us from doing what we can to help those who have AIDS and to limit its spread. For the next decades, we will clearly have our hands full: seeking effective biomedical responses to HIV; searching for effective means of modifying sexual and IV-drug-related behavior; giving a higher priority to limiting the transmission of AIDS; treating humanely, compassionately, and generously the millions who will sicken and die of this affliction.

Living with AIDS, then, does not mean resigning ourselves to AIDS. But it does mean readying ourselves for the long haul. It means preparing for a prolonged and often disheartening effort that will produce no dramatic victories—an effort that will last decades, generations, and probably for the rest of human history.

ENDNOTES

I am grateful to Marcia Angell, Suzanne Berger, Lincoln Chen, Stephen Graubard, David Guston, William A. Haseltine, Kenneth Manning, and Leo Marx for their comments on an earlier draft.

[1]Flyer announcing the publication of *AIDS, Sexual Behavior, and Intravenous Drug Use*, by the Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences (Washington, D.C.: National Research Council, 1989).

[2]Studies of the social interpretation of epidemics and diseases abound. See, for example, W. McNeill, *Plagues and Peoples* (Garden City, N.Y.: Anchor Press, 1976); A. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880* (New York: Oxford University Press, 1987); S. Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1989); C. E. Rosenberg, *The Cholera Years: The United States in 1832, 1849, and 1866* (Chicago: University of Chicago Press, 1987); and S. L. Gilman, *Disease and Representation: Images of Illness from Madness to AIDS* (Ithaca, N.Y.: Cornell University Press, 1988). At the extreme, for instance, studies by such people as Sontag and Gilman view images of disease as nothing but social projections. See, for example, Sontag's argument in *AIDS and its Metaphors* (Washington, D.C.: National Research Council, 1989). The pessimism with regard to the prognosis of HIV infections is the result of a misplaced medical metaphor.

[3]Remarks at Morison Symposium "AIDS: Long-Term Prospects," Massachusetts Institute of Technology, 7 February 1989.

[4]This general account is based on Institute of Medicine and National Academy of Sciences, *Confronting AIDS, Update 1988* (Washington, D.C.: National Acad-

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emy Press, 1988), and the special issues on AIDS of *Science* 239 (5 February 1988) and of *Scientific American* 259 (October 1988).

[5]See Institute of Medicine, 42–45; J. W. Curran et al., "Epidemiology of HIV Infection and AIDS in the United States," *Science* 239 (5 February 1988):610–16; W. L. Heyward and J. W. Curran, "The Epidemiology of AIDS in the U.S.," *Scientific American* 259 (October 1988):72–81. Heterosexual transmission efficiency appears to be higher in Africa than in America for reasons that may be related to the greater prevalence in Africa of other sexually transmitted diseases. See P. Piot et al., "AIDS: An International Perspective," *Science* 239 (5 February 1988):578–79. The efficiency of sexual transmission also probably varies with the stage of the HIV infection, overt AIDS symptoms producing the high rates of infection.

[6]Throughout this account, I use the current estimate of a median of 9.8 years from infection to death (*New York Times*, 23 March 1989) for adults with HIV. This figure is necessarily based on projections, given the recency with which HIV has been identified. Initial infection with HIV is sometimes associated with a transient flulike illness. Later stages entail swollen lymph nodes followed by subclinical immune dysfunctions. During these stages, which usually last many years, those with HIV generally feel well and, absent medical tests, are unaware of illness. See R.R. Redfield and D.S. Burke, "HIV Infection: The Clinical Picture," *Scientific American* 259 (October 1988):90–98.

[7]This conclusion, although once disputed, is increasingly accepted. It is consistent with the mounting evidence that over time, the number of seropositive patients who develop AIDS symptoms increases steadily. Even more decisive are studies that show that "the longer people with HIV are followed, the more likely it is that they will have moved to a severer stage of disease" (see Redfield and Burke, 96).

[8]See Institute of Medicine, 49–50.

[9]See J. M. Mann et al., "The International Epidemiology of AIDS," *Scientific American* 259 (October 1988):82–89; and Heyward and Curran.

[10]In no industrial nation has an adequate sample of blood been tested for seropositivity. American data are largely from military recruits, blood donors, and women giving birth. The resulting seropositivity rates are very low: e.g., for 1985–1986, they were .15 percent (1.5 per 1000) in 466,629 military recruits tested. But in older groups, seropositivity by rates are higher: e.g., .44 percent in recruits over the age of twenty-six; 1.01 percent in recruits over twenty-six from the middle Atlantic states. In interpreting such data, the active deferral of recruits at risk of HIV because of homosexuality, IV drug use, or hemophilia should be remembered. See R. R. Rivera, "The Military," in H. L. Dalton and S. Burris, eds., *AIDS and the Law, A Guide for the Public* (New Haven: Yale University Press, 1987), 233–34; and Curran et al., 613.

[11]See Piot et al.; Curran et al.; Mann et al.; and Institute of Medicine, 46–50.

[12]On therapy and prophylaxis, see R. Yarchoan et al., "AIDS Therapies," *Scientific American* 259 (October 1988):110–19; W. A. Haseltine and F. Wong-Staal, "The Molecular Biology of the AIDS Virus," *Scientific American* 259 (October 1988):52–63; and Institute of Medicine, 130–40. The authors of the last work say that "much of the information that emerges from ongoing studies highlights

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the difficulties that must be overcome before effective prophylactic or therapeutic interventions are feasible" (p. 130).

[13]W. Haseltine, remarks to Morison Symposium.

[14]Surgeon General C. Everett Koop has warned that an AIDS vaccine is not likely before the year 2000. See T. J. Matthews and D. P. Bolognesi, "AIDS Vaccines," *Scientific American* 259 (October 1988):120–27; and Institute of Medicine, 141–46. The authors of the latter volume note that "the pessimism expressed [two years ago] about the likelihood of a licensed vaccine becoming available within the next 5 or 10 years has not been mitigated by the accomplishments of the last 2 years" (p.146).

[15]W. Winkelstein et al., "Sexual Practices and Risk of Infection by the Human Immunodeficiency Virus: The San Francisco Men's Health Study," *Journal of the American Medical Association* 257 (1987):321–25; and H.V. Fineberg, "Education to Prevent AIDS: Prospects and Obstacles," *Science* 239 (February 1988):592–96.

[16]For an analysis of the presidential, bureaucratic, and congressional responses to AIDS, see D. Guston, *Institutional Tensions in the Federal Government's Response to AIDS* (Cambridge: Department of Political Science, Program in Science, Technology, and Society, Massachusetts Institute of Technology, January 1989). AIDS was first identified in 1981. President Reagan first mentioned it in 1985; in 1986 he termed it a major health priority; on May 31, 1987, he delivered his first major address on the subject. On the slowness of the federal response to AIDS, see also, e.g., *AIDS Education, Activities Aimed at the General Public Implemented Slowly*, Report of the General Accounting Office, HRD-89–21 (16 December 1988).

[17]L. Chen, remarks at Morison Symposium.

[18]Because of the increasing association of AIDS with IV drug use, American blacks and Hispanics are currently overrepresented by a factor of two or three among seropositive people and people with AIDS. If, as is believed, gay males have reduced their risks of contracting AIDS but IV drug users have not, this disproportion is likely to increase. See Curran et al., 612; and Institute of Medicine, 46–47, 49.

[19]See the analysis of M. A. R. Kleinman, "AIDS, Vice, and Public Policy," Working Paper 87–04–02, Kennedy School of Government, Harvard University, Cambridge, October 1987. Kleinman imagines policies that would limit the transmission of AIDS if no other priorities were in competition: e.g., dispensing free, nonreusable needles to IV drug users and testing the entire population for seropositivity and providing everyone with electronic bracelets that beeped in the presence of another bracelet with a different seropositivity.

[20]See R. Shiltz, *And the Band Played On* (New York: St. Martins Press, 1987), for an account of the bathhouse controversy. The fragility of sexual freedom for homosexuals is underlined by the illegality of sodomy in half of the United States, and by the recent Supreme Court decision upholding the constitutionality of Georgia's antisodomy statutes.

[21]The fear of discrimination against those who have AIDS or who test positive for HIV stands in the way of both mandatory and voluntary testing, and impedes

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many educational efforts. Two states, California and Massachusetts, have passed laws protecting the confidentiality of HIV test results; in most of the rest, the confidentiality of such results is unclear. See the recommendations on discrimination and confidentiality in the *Report of the Presidential Commission on the Human Immunodeficiency Virus* (Washington, D.C.: June 1988):119–27, and of Institute of Medicine, 62–64, 71–74. See also Dalton and Burris.

[22]See Sontag, *AIDS and Its Metaphors*.

[23]C. E. Rosenberg, "What Is an Epidemic? AIDS in Historical Perspective," *Dædalus* 118 (2) (Spring 1989):1–19.

[24]The difference is of course relative. Every disease manifests itself differently in different individuals and in different social settings. What distinguishes HIV, however, is that so many of its symptoms are not those of the retrovirus itself but rather those produced by the vulnerability of the body to any of a host of opportunistic infections and conditions. On the varied symptomatology of AIDS, see Institute of Medicine, Appendix B, 202–17.

[25]This prediction is widely accepted, though seldom stressed. For example, the authors of *Confronting AIDS, Update 1988* note, in discussing the need for better data, that "it is widely accepted that the number of AIDS cases will continue to grow for many years, probably into the next century" (p. 60).

[26]A more precise estimate of course depends on the death rate in each successive year following infection. If it is constant at, for example, 5 percent a year from the date of infection, then a ten-year lag is predictable. But if it should peak in, for example, the thirteenth year, a downturn in deaths would only occur in the fourteenth year. Further complicating all predictions is the finding that infectivity may be greatest in the later, symptomatic stages of HIV. If so, then any demographic increase in symptomatic AIDS would tend to produce a surge in transmission. See R. M. May, R. M. Anderson, S. M. Blower, "The Epidemiology and Transmission of HIV-AIDS," *Dædalus* 118 (2) (Spring 1989):163–201.

[27]M. Angell, remarks at Morison Symposium. If, however, the early "silent" stages of HIV are accompanied by lower infectivity than the symptomatic stages, doubling the life expectancy of seropositive individuals would increase transmission rates by less than a factor of two. It is also possible that antiviral agents might reduce or prevent the transmission of HIV.

[28]Cited in Piot et al., 574, footnotes 15 and 16.

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Prospects for the Medical Control of the AIDS Epidemic

THE ACQUIRED IMMUNE DEFICIENCY SYNDROME is caused by an infectious microorganism, a virus called the human immunodeficiency virus type 1 (HIV-1). Infection by the virus initiates a slow progressive degenerative disease of both the immune and the central nervous systems. Seven to ten years usually separate infection from the appearance of serious disease symptoms. During the disease-free period, the infected people may transmit the virus to others. Almost all those infected eventually develop terminal disease. It was estimated that by the end of 1988, between 10 million and 20 million people worldwide were infected by the virus.

What protection does medical science offer? In this article I present a summary of the current status of diagnosis, treatment, and prevention methods and of the prospects for the development of additional means to control the epidemic. As an introduction to medical control strategies, the disease process, starting with infection, is described.

THE DISEASE

AIDS is a disease acquired by infection with HIV-1. Those who are not infected do not develop AIDS. Almost all those infected with the virus eventually develop life-threatening illness. A search for the effects of life-style, diet, and exposure to other infectious diseases has

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failed to turn up influences that accelerate or retard the onset of AIDS. The only important factor for progression appears to be the time elapsed from the initial infection.

The course of infection can be rapid in infected infants. About half the children infected at birth die within a year or two. Some infected children live longer. What determines rapid or slow disease in children is not understood.

There are at least two life-threatening direct effects of infection: depletion of the immune system and destruction of the central nervous system. Serious immunological damage occurs by depletion of a specific type of immune cell, a white blood cell called a helper T lymphocyte. The helper T lymphocyte is also called the $CD4^+$ helper T cell, CD4 describing a structure that is present on the cell surface and the plus sign signifying the presence of the protein on the cell surface. The helper T cell coordinates the defense to infection. The destruction of the helper T cell population by the virus paralyzes much of the immune system. A steady decline in the number of helper T cells is the most reliable indication of serious immunological disease. Eventually, the helper T cell population disappears and the body is left virtually defenseless against a wide range of diseases.

In many, infection of the central nervous system with the AIDS virus often causes progressive destruction of the brain and spinal column. The size of the areas of the brain and spinal column that are destroyed increases over time, and severe cognitive and motor dysfunctions may result.

Infection also induces a profound wasting disease. Dramatic weight loss occurs independent of caloric intake. Death may occur from infections that are a consequence of loss of immune function, from starvation, or from functional failure of the central nervous system.

Patterns of Virus Infection

Three patterns of growth of the virus after infection have been described in medical literature. In a majority of the cases studied, the virus grows rapidly within the first few weeks of infection. During this time the virus spreads throughout the body. The virus can be recovered in the fluids surrounding the brain and the spinal column before it can be detected in the blood. During this period the virus also infects many different types of immune cells, including the helper

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T cells. Other types of immune cells that clear up cell debris, called macrophages, as well as immune cells that present foreign substances to the immune system, dendritic cells, are infected.

The effects of early virus replication range from slight to severe. Most people experience mild flulike symptoms and swollen glands upon initial infection. There are rare cases of severe rashes and meningitis associated with initial infection.

After three to six weeks the infection begins to abate. The amount of virus present in the blood and the central nervous system drops to a very low level. The symptoms of infection also disappear, with the exception of swollen lymph nodes, which may sometimes persist. A drop in the amount of circulating virus marks the beginning of the asymptomatic period. During this period infected people appear to be healthy and are usually unaware that they are infected. It is estimated that 95 percent of those infected with the AIDS virus in the United States do not know that they are infected, as they show no signs of disease and have not been tested for anti-AIDS virus antibodies.

During the asymptomatic period virus growth continues at a very low level. This state is called controlled or quiet infection. At this time the infection may be transmitted to others. The onset of the terminal phase of disease, when damage to the immune and central nervous systems occurs, is marked by a reemergence of the virus. The amount of virus rises over three to six months and remains high until death. The close association of persistent high-level virus production with the onset of serious disease symptoms is strong evidence that growth of the virus itself causes the damage to the immune system and brain. The observation that the AIDS virus selectively destroys helper T cells when it is grown in the laboratory supports the theory of direct tissue destruction by the virus. The body's reaction to such a massive persistent viral infection may also be responsible for some of the tissue damage.

In 1 out of 5,000 people, evidence of virus growth disappears. Despite the absence of virus growth, the information necessary to make the virus remains in blood cells. This state is called silent infection. People are healthy during silent infections. It is not known whether the virus can be transmitted to others sexually or by blood transfusion during the silent infection state.

The existence of such silent infection offers hope for treatment of those infected with the AIDS virus. If a natural state of silent infection

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occurs spontaneously, it may be possible to induce silent infections artificially.

The third pattern of infection is one in which silent infections become quiet infections. Examples of such changes are rare and this pattern has been described only recently. The tests for silent infection are new and their reliability is uncertain. Careful documentation of the third pattern of infection is needed. The existence of such silent infections indicates a need for diagnostic tests that detect viral genetic information in the absence of defective virus or antiviral antibodies.

The Immune Response to Infection

An immune response to virus infection usually occurs within several weeks of infection. The body protects itself from invading microorganisms in at least two ways. One set of cells produces substances that recognize shapes on the surface of the foreign microbe. These substances, called antibodies, are made by white blood cells called B lymphocytes. Antibodies are very specific in their binding. Each one binds only to a very specific structure.

Antibody binding to the surface of a microorganism causes the destruction of the invader by several different means. The antibodies serve as signals that attract other cells, notably macrophages that engulf and digest the microbe. Antibodies also attract another type of white blood cell called killer T cells. The killer T cells release toxic substances that may destroy the virus or cell recognized by the antibodies. Antibodies also aggregate with one another along with the microbe. The large aggregates may be removed by filtration from the blood. In addition, antibodies bound to the surface of a microbe initiate a chain reaction whereby other blood components mobilize to kill the microorganisms so identified.

The second major arm of the immune response is the recognition of invading microbes by a separate class of white blood cells. This is another function of the killer T cells. They have substances on their surfaces that recognize foreign organisms. These cells remain close to the organisms that they recognize and secrete toxic substances.

Both components of the immune system are activated by AIDS virus infection. The antiviral antibodies to the AIDS virus are made within several weeks of infection. The concentration of these antibodies, especially those that recognize the outside of the AIDS virus, rises to a very high level and remains very high throughout the

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remainder of the infection. A cellular immune response to the AIDS virus also occurs. Within two to three months after infection, killer T cells that recognize components of the AIDS virus are detected. The killer T cells also persist for much of the time a person is infected and only disappear near the very end of the disease process.

The strength of the immune response to AIDS virus infection proved to be a surprise. Very high concentrations of antiviral antibodies are found throughout infection. The activity of the killer T cells is also exceptionally high in comparison with the activity associated with most other types of infection.

It is likely that the initial resolution of most infections, the phenomenon whereby the concentration of virus falls several weeks after initial infection, is due to the immune response. Circulating virus as well as virus present within cells is killed and cleared from the body. The clearance of virus is not complete as some cells remain infected and continue to produce virus. The failure of the immune system to completely clear the virus from the system accounts, at least in part, for the observation that once a person is infected by the AIDS virus, that person is infected for life. Despite the vigorous immune response to infection, viruses continue to be produced and most people remain capable of infecting others. Eventually, immune protection fails and people die from the effects of unrestricted virus growth.

The trigger that causes the reemergence of prolific virus production in the face of this immune response is not fully understood. It is possible that the persistent low levels of virus production finally cause enough damage to the immune system that it can no longer keep the virus under control.

Transmission

An understanding of the mechanism of transmission of the virus is important for the design of prevention strategies. There are three known means by which the AIDS virus may be passed from one infected person to another. The AIDS virus is transmitted venereally. The virus may be transmitted from an infected woman to a man or from an infected man to a woman or to another man during sexual contact. The virus is transmitted in both directions by vaginal sex. Several studies have shown that the likelihood that either sex partner will be infected is about the same in heterosexual couples that

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practice only vaginal intercourse. The virus is transmitted to the receptive partner by both anal and oral sex.

Early studies of transmission of the virus in the population of male homosexuals suggested that breaks in the mucosal membrane might be necessary for the virus to gain access to the body. A number of more recent studies indicate that the virus can gain entry in the absence of such breaks. It is now known that the AIDS virus can infect a variety of immune cells that are not present exclusively in the blood. Some of these cells, including monocytes, macrophages, and dendritic cells, can also be found at the mucosal surface. Virus may infect such cells at the surface and thereby gain access to the rest of the body, as many of these cells can move from one tissue to another or be in contact with other motile cells. The infection initiated at the surface may spread as the infected cells move first to the lymph nodes and then to other tissues, including those of the brain.

A clear example of infection across the intact mucosal membrane is the infection of a chimpanzee infected by gentle application of a solution of the AIDS virus to the vaginal surface. Infection with a virus similar to the AIDS virus, the simian immune deficiency virus, has also been initiated by gentle application of virus solutions to the vaginal, penile, or rectal mucosa of Rhesus monkeys. Evidently, virus and perhaps virus-infected cells present in seminal and vaginal fluids can initiate infection across intact mucosal membranes.

The efficiency of infection by sexual exposure is not high. It is estimated that infection occurs in less than 1 in 200 contacts between infected and uninfected people. The reason for the low transmission frequency is not clear. It is possible that infection requires exposure to a high concentration of virus and that such concentrations are only rarely present in vaginal and seminal fluids.

Transmission by blood donations is efficient. Almost all those who receive blood from HIV-1 infected people become infected themselves. Similarly, people who receive HIV-1 infected organs are almost always infected.

The AIDS virus is also transmitted by concentrated blood preparations that contain blood-clotting factors needed to treat hemophilia. The ability of the virus to survive the freeze-drying procedures used for preparation of the clotting factors came as a surprise. It is now known that the AIDS virus is stabilized by high concentrations of blood proteins and can remain active for weeks in dried blood. The

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efficiency of blood-to-blood transmission and the stability of live virus in dried blood contributes to the spread of the virus by nonsterile needles and syringes. More than 60 percent of intravenous drug users in Europe and the United States are infected.

The AIDS virus can be transmitted from an infected mother to her newborn child. About one-third to one-half the children born to infected mothers will become infected. It is likely that most of the infections occur either during birth or while the child is being breast fed. Apparently, most children are not infected during pregnancy. Infection of newborns represents a rapidly growing problem. More than one-fourth of mothers infected in some central African cities and more than 5 percent of mothers in some urban centers in the United States are infected. Such high infection rates threaten the continued existence of entire populations.

DIAGNOSIS

Diagnosis for AIDS means detection of infection prior to the development of obvious disease symptoms. Diagnosis of infection in the absence of clinical symptoms of disease is an important public health measure, for throughout the period of apparent health, infection can be transmitted to others through sex, birth, shared needles, or blood and organ donations.

The technical problem of diagnosis of infection has been solved, at least for practical purposes of control of the epidemic. Further diagnostics improvements in detection methodology will facilitate detection of a few infections that are currently missed. The first AIDS tests were designed to protect the blood supply. These tests were meant for use on whole blood and were not intended primarily to serve the needs of individual patients and their physicians. A new set of tests, designed specifically for individuals, became available in 1988. Additional AIDS tests are being developed.

The initial AIDS tests relied on the use of relatively impure preparations of virus to detect antiviral antibodies. These HIV-1 antibody detection tests do not detect the virus itself. The tests are generally effective because most people make high levels of antibodies to parts of the outside of the AIDS virus. Even though the structure of the AIDS virus may vary from person to person, the specific parts of the virus that are most often recognized by a patient's antibodies

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remain constant. Invariance of the antibody recognition sites underlies the ability to detect the AIDS virus infection with test components made from a single prototype strain of virus.

A two-tiered system for detection of infection is now used. The first tier detects antibodies that react with a crude mixture of virus proteins. This test is repeated twice to reduce the frequency of operator and equipment errors. If the first two tests detect antiviral antibodies, a second type of test is used. The second test measures the ability of antibodies to recognize separated components of the virus, a procedure called a confirmatory test. The confirmatory test is more specific than the original screening tests, as the reaction of the antibodies to several partially purified virus components is detected simultaneously.

If used properly, the procedure can yield less than one false positive for 100,000 samples tested, even if the rate of infection in the test population is very low. In practice, the rate of false positive tests is much higher, mostly the result of poorly trained and poorly supervised personnel.

Substantial improvements in antibody detection have been made recently. The early preparations of virus were very impure. Often less than 5 percent of the total material in the test was virus. The impurities in the preparation sometimes reacted with antibodies that were present in the blood of normal people. Such reactions led to false positive test results.

A new set of AIDS antibody tests has been developed. These tests include very highly purified subcomponents of the virus. Selected bits of the virus's genetic material are transferred to bacteria that produce large amounts of individual AIDS virus proteins. The purity and concentration in the test components improves the sensitivity of the test and reduces the number of false positive results.

New test formats are also possible using the pure test ingredients. Very simple test procedures requiring no machinery have been developed. These tests can be done under rough field conditions. The results of such tests are available for interpretation within five minutes. The amount of blood needed is so small that one drop from a finger prick suffices. The new tests will permit diagnosis of HIV-1 infection in rural areas where sophisticated machinery is not available. The new tests are also suitable for use in a doctor's office. They might be used on the initial visit to the office to determine that a

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patient is not infected. Positive tests using the rapid techniques will still require confirmation through a different method of detection.

Home Testing

The technology of HIV-1 antibody testing is nearing a time where test kits such as those used for early detection of pregnancy can be made. Slight variations in some existing methods could serve this purpose. For example, an organization could provide, on a confidential or an anonymous basis, information regarding antibody status. Social and health-care policies regarding home testing should be developed with the likelihood that such tests will be available shortly.

Filling the Gaps

For several reasons, the antibody detection test may fail to detect some HIV-1 infection. The presence of the virus precedes the antibody response immediately following infection. The concentration of AIDS antibodies in some patients may also be too low to detect using the current tests. Some people harbor the AIDS virus genetic information but do not make antibodies to the virus.

The fraction of infections that cannot be detected by the current generation of antibody tests is not known but is believed to be very small. Most people appear to make antibodies within the first six months of infection. As most infections last ten years or more, substantially less than one in twenty people slips through the screening procedures for this reason. The number of those who are not detected is thought to be even lower because most people make antibodies to the virus from the first six to eight weeks after infection. A retest after six months is often recommended.

Several methods exist to detect the virus itself. The AIDS virus contains two types of components useful for detection of the proteins that comprise the virus particle and the genetic information of the virus, an RNA polymer. Tests for detection of the most abundant viral protein, called protein 24 (p24), have been developed. Protein 24 can sometimes be detected shortly after infection before the antibodies to the virus are made. During the asymptomatic phase of infection, the concentration of virus in the circulation is usually so low that p24 cannot be detected. Substantial improvements in the methods for virus protein detection are possible. However, such improved tests are expensive and difficult to perform. It is likely to be

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five years or more before substantially improved tests for virus proteins are available for blood-bank use. Sensitive means to detect viral RNA exist and are being improved. Reliable tests for RNA detection are not yet available even for use in experimental settings. For this reason, it is also likely that tests for viral RNA will not be available to blood banks and physicians for five years or more.

It is possible to isolate live virus from infected people. The ease of virus isolation appears to depend on the stage of infection. Virus is often readily isolated immediately after initial infection and late in the disease process. It is often difficult to isolate virus during the asymptomatic period. The procedures for virus isolation are cumbersome and not easily standardized. These tests are available only in specialized facilities. The difficulties and hazards of virus isolation preclude the use of virus isolation in doctors' offices.

Novel Antibody Detection Tests

Recent studies of antibody response to infection have shown that most people make a very early antibody response to two viral proteins that are not present in the first or second generations of antibody tests. These proteins are called the *vpu* and the *nef* proteins. They are made in virus-infected cells but are not incorporated in the virus particle itself. The antibodies to these proteins are made very early in virus infection.

Tests that include portions of the envelope protein of the virus as well as purified *vpu* and *nef* proteins will be useful for the diagnosis of AIDS in some patients whose disease cannot be detected with current methods. The methods that can be used for detection of *vpu* and *nef* proteins are similar to those currently used in blood banks and doctors' offices. Such tests could be developed for use in blood banks and doctors' offices. They may be available by 1990 or 1991. Systematic use of these tests would reduce still further the number of undetected HIV-1 infections.

Detection of Silent Infection

The public health consequences of silent infection are unknown. The phenomenon was discovered so recently that many of the basic facts regarding this state of infection are simply not known. For example, we do not know whether people who harbor silent infections are at risk for development of subsequent disease. Conversion from the

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silent to the controlled state of infection has been observed. It is not clear whether controlled infection represents reactivation of the silent virus or an altogether new infection resulting from a new exposure. Careful analysis of the genetic information of the virus during silent infection along with that present during the controlled infection may resolve this issue.

Detection of the stable DNA form found in the blood cells provides one means of diagnosing silent infection. Until recently it was not possible to detect silent infections, even in experimental laboratories, as neither antienvelope antibodies nor virus particles are present. The advent of a new detection method, called DNA amplification or polynucleotide chain reaction (PCR), can detect very small amounts of viral DNA. The PCR method amplifies greatly the amount of a specific DNA in a sample. Viral DNA can be detected when it is present in less than one part per billion. At present, PCR technology is not suitable for use in blood banks or in a doctor's office because it is technically demanding. The method is so sensitive that care must be exercised to avoid false positive responses resulting from contamination from previous tests. Standardized procedures for use of PCR are now being developed. The PCR method is so new that it is not yet used for any routine laboratory tests.

It is likely to be several years before improvements are made that permit the PCR method to be used in blood banks or by private physicians. The potential usefulness of this test method for diagnosis of HIV-1 infections, as well as for the diagnosis of many opportunistic infections associated with AIDS, is so great that PCR is likely to be widely used in the future.

There is a recent report that some people may continue to produce antibodies to the *nef* protein of the AIDS virus during periods of silent infection. If these reports are confirmed, detection of *nef* antibodies may also serve as a useful indicator of silent infections. Rapid antibody test kits for *nef* detection should be available for clinical tests in 1989. However, the early encouraging results must be followed by systematic studies before *nef* antibody detection becomes possible.

Predictive Diagnostics

A predictable pattern of disease occurs in most HIV-1 infections. The timing of onset of each new disease stage is difficult to predict largely

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because the time of initial infection is not usually known. Variations of two or more years in the rate of progression are also common.

It will be useful to develop diagnostic methods that are predictive of the disease course. The earlier the warning of onset of serious disease symptoms, the more useful the diagnostic method will be for planning early intervention strategies. Currently, the progress of the disease is judged by the appearance of clinical symptoms and the measurement of the absolute number of T cells. These measures provide an accurate indication of current disease status but are not reliable early predictive indicators.

A variety of new tests is now being evaluated for the ability to predict a change of health status one to two years early. Most of these tests measure details of the antibody response to HIV-1 proteins. Although most people make some antibodies throughout to HIV-1 infection, the details of the response to individual viral proteins, and even to subregions of the viral proteins, differ from person to person and throughout the course of infection. There is some evidence that the details of the antiviral antibody response can predict future health or disease. A battery of specialized tests will probably be needed for such determination. Prototypes of many of these tests have been developed. It is likely that predictive tests will become commonplace as treatment improves.

TREATMENT

Effective treatment for HIV-1 infection has not yet been developed. Some progress has been made in slowing the terminal phase of the disease. Progress in the development of treatments that lengthen the disease-free period of those already infected with HIV-1 is anticipated. Progress has also been made in treatment of opportunistic infections and opportunistic cancers that result from impaired immune function. Despite the relatively early stages of AIDS therapy, certain conclusions regarding the nature of probable future AIDS therapies can be reached, conclusions that may have profound consequences for health delivery systems.

Infection with the AIDS virus is lifelong, a consequence of the nature of the virus infection. No procedures exist that can be adapted easily for eradication of the virus. The virus implants itself permanently into the genetic material of the cell. A number of interesting

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but highly speculative solutions to this problem have been suggested. These proposals rely on advances that are anticipated in fundamental biology and pharmacology. Many of the concepts are so new that critical parts of the procedures have not been tested. A fully curative treatment for HIV-1 infection that eliminates all virus information lies many years in the future. Until progress in virus eradication is made, AIDS will require lifelong treatment. The care of those infected with HIV-1 is likely to be comparable to the treatment of conditions such as chronic kidney disease, chronic hepatitis infection, and diabetes.

Clinical Trials

The immediate goal of treatment for AIDS and asymptomatic infected people is to control virus replication and eliminate opportunistic infections and tumors. The fundamental assumption of such treatment is that elimination of prolific virus replication will arrest the infection and prevent further damage to the immune and central nervous systems. It may not be necessary to inhibit virus replication completely to maintain health. Control of the virus infection is likely to require continued administration of antiviral drugs. Patients undergoing such treatments will require continued medical observation, as each of the drugs used is likely to have adverse side effects.

The consequences of successful treatment should be anticipated. The development of treatment for those who are infected with HIV-1 but are not yet ill is very likely to increase dramatically the number of people who will demand such treatment. More than 2 million people in the United States are infected with the AIDS virus. Between 15 million and 20 million people are thought to be infected worldwide. The number of those infected is likely to increase appreciably before successful therapies are developed. If a successful treatment is developed, the incentive for being tested for HIV-1 infection will also grow appreciably.

Eventually, it may be possible to induce a state of silent infection by using antiviral therapy. The silent infections so produced are the equivalent of remissions induced by cancer therapies. Patients in virus remission would be monitored regularly for evidence of reoccurrence of viral replication. It may be possible to treat people with antiviral agents only when virus growth reemerges. The prospect of induced

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silent infection is the most optimistic projection for future therapies. Presently it is not possible to achieve HIV-1 remission.

Many years will probably be needed before methods for controlling the infection are perfected. The major factor that will ultimately limit the rate of progress is not the discovery of a set of effective antiviral drugs but, rather, the slow progress of the disease itself. Almost three years were required to determine that AZT, at present the only drug approved for the treatment of AIDS in the United States, could extend the life of someone with AIDS by as much as one year. An even longer time will be required to determine whether a drug can slow down or prevent the onset of serious illness in asymptomatic HIV-1 infected people. The progress of the disease is so slow that a minimum of four to five years will be needed for each trial. The only major trial currently in progress for the asymptomatic individual is a test of the effectiveness of chronic administration of AZT. More than 5,000 people in the United States and almost as many in France and the United Kingdom will participate in this trial. The first results may be available by 1991.

Preclinical Drug Development

There are three methods of drug discovery. The first is a near-random test of substances for the ability to prevent virus growth. Pure chemical compounds as well as extracts of plants, animals, and microorganisms are tested. The goal of this screening program is to discover compounds that slow the growth of the virus and that are not toxic to normal cells. Once such compounds are found, hundreds of analogues are made. The analogues with the most desirable properties are evaluated for toxic side effects in animals prior to an initial test in people with AIDS.

The advent of biotechnology permits significant improvement and expansion of the traditional screening methods. With recombinant DNA technology, each component of the AIDS virus can be prepared in large amounts. The ability of compounds to interfere with the function of each subcomponent is examined. The use of isolated subcomponents improves the screening procedures, for the inhibition of an isolated virus function can be studied. Many of the new screening procedures can be fully automated. Crude mixtures of chemicals can also be tested for the potential to inhibit virus

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replication. At present many plant and animal extracts are too toxic to be tested in live cells.

The rapid explosion of knowledge about the structure and function of the AIDS virus has laid the foundation for rational drug design. The potential targets for antiviral drugs include the proteins that make up the virus particle itself as well as proteins made by the virus that regulate virus replication. More than fifty specific targets have been identified. A drug that inhibits any of these target functions limits virus replication.

Many of the functions needed for virus production are specified by the cell rather than by the virus. For the cell, some of these functions may be dispensable. Drugs that inhibit such cellular functions are also being developed as potential anti-AIDS drugs.

Studies of the detailed mechanism of action of each viral component are under way. This research is well funded and proceeding rapidly. The information emerging from these studies has already begun to affect the design of new drugs.

By the end of 1990 several dozen promising candidate drugs will very likely be available. The number of potential drugs will continue to rise thereafter. The challenge for the medical community will then be to implement the clinical tests needed for drug approval. A major expansion of the clinical trials program in both the United States and the world is needed.

Immunotherapy

It may prove possible to stimulate the immune system in those already infected with HIV-1. Such stimulation may provide some measure of protection from progressive disease. The existing immune response only slows the progression of disease. Ultimately, those infected with the virus become seriously ill despite the immune response that is made. Studies of the immune reactions to the virus infection show that only limited portions of the proteins of the virus are recognized by the immune system. A careful catalogue of these natural sites of immune recognition is now being made. Once these sites are fully known, it may prove possible to design modified proteins that elicit immune responses to regions of the virus that are normally hidden. Some of these responses may provide additional means of slowing down prolific virus replication. The first attempts

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to improve the immune response in people with AIDS and in HIV-1 asymptomatic people are in progress.

A Coordinated Research Effort

The effort to discover new anti-AIDS drugs currently involves between one-third and one-half of the largest drug manufacturers. More than 100 small companies are also involved in anti-AIDS drug development. There are more than 200 university, medical school, and private research foundation laboratories in the United States participating in the search for anti-AIDS drugs.

A major portion of the preclinical drug-development program in the United States is coordinated by the National Institutes of Allergy and Infectious Disease and the National Cancer Institute. Communication of novel approaches and progress within the federally financed drug-development group, called the National Cooperative Drug Discovery Group (NCDDG), is effective. The National Cooperative Drug Discovery Program was organized in 1986. Significant coordinating national efforts for anti-AIDS drug development were implemented in the United Kingdom and France in late 1988.

PREVENTION

Vaccination has proved to be an effective means for the prevention of infectious diseases. Vaccines stimulate the immune system to recognize microorganisms. Once stimulated by a vaccine, the immune system responds as if infection had already occurred. Normally, ten days or more are required to raise protective responses to new infections. In a vaccinated person an effective immune response can be made within one or two days following exposure. The major advantage of a vaccine is that it can be given before infection occurs. Most vaccines need be given only once every few years. Vaccines have been developed for a number of viral diseases, including small pox, yellow fever, polio, measles, and chicken pox.

Vaccination

Efforts to develop an AIDS vaccine have encountered difficulties. Ordinarily, killed or weakened virus is used. In some cases, subcomponents of the virus are used rather than the entire killed virus. The initial tests of the vaccine are usually done in animals. The response

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to the vaccine in animals is evaluated by measuring the production of antiviral antibodies. The effectiveness of a vaccine is measured by exposing the animal to live, disease-causing organisms. A vaccine is successful if the dose of the virus needed to establish infection is substantially increased in a vaccinated as compared with an unvaccinated animal. Absolute protection from viral infection is rarely achieved. If the vaccine proves to be effective in animals, it is then tested in people.

The traditional vaccine procedures have been tried for both HIV-1 and the simian immuneodeficiency virus (SIV), a virus that causes an AIDS-like disease in monkeys. The HIV-1 vaccines have been tested in chimpanzees, the only animals other than humans that can be readily infected with the virus. SIV vaccines have been tested in several types of monkey. Vaccine preparations have included killed virus as well as virus subcomponents.

In most cases a very good immune response is made to the vaccine preparation. High concentrations of antiviral antibodies are detected following inoculation with the vaccine. Responses of other immune cells have also been detected in vaccinated animals. Despite the vigorous immune response, vaccinated chimpanzees and monkeys do not resist infections. Chimpanzees that make immune responses to the vaccine can be infected by modest doses of virus. The results in other monkeys are also disappointing. Evidently, the immune response that is made to vaccines is not protective.

The AIDS virus evades the immune response by several means. The outside of the AIDS virus is completely covered by a coating of sugar. The sugar coating closely resembles the surface of normal cells and does not entirely protect the outside of the viral protein from immune recognition. At least two parts of this protein elicit vigorous antibody responses. One of the regions is located in the interior of the protein and is not present at the surface of the virus particles. This region stimulates the immune response only when the virus falls apart. Since this region is hidden in the assembled virus, antibodies made to this region are harmless.

The second area recognized by antibodies is exposed to the surface of the functioning virus. Antibodies to this region do inactivate the virus. However, this portion of the virus changes rapidly. The changes in this region prevent recognition by antibodies. Changes in

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the virus in this region may outpace the ability of the immune system to respond.

There are several other features of the AIDS virus that contribute to the difficulty in vaccine development. Some cells contain virus information but do not produce virus. Such cells are invisible to the immune system. Virus may enter a latent state and reemerge when immunity is lowered.

It is possible for the virus to spread from cell to cell. Many of the cells infected by the AIDS virus wander freely throughout the body. These cells may not produce virus except when they are in direct contact with other cells. In such a case, virus may be transferred from one cell to the other and never be visible to the immune system.

Many natural infections by HIV-1 occur at mucosal surfaces. A specialized set of antibodies and immune cells must be mobilized for protection at such surfaces. Experience with the development of vaccines to protect against surface mucosal infections is limited.

The difficulties encountered in the vaccine program are not unique to the AIDS virus. Attempts to develop vaccines for the herpes simplex viruses and the mononucleosis virus are similarly troubled. It has not been possible to make vaccines that prevent infection by the malaria or syphilis parasites. All these organisms share the ability to establish long-term infections in people.

Current attempts to develop vaccines focus on the development of substances that will produce a different type of immune response from that which is naturally made. It is evident that natural immunity is not fully protective. Substantial progress has been made in understanding the fundamental principles of immune recognition. Progress has also been made in understanding the function and structure of the AIDS virus proteins. These insights are now being used to design second- and third-generation vaccines. Success of this effort is not guaranteed. When, or even if, a successful vaccine will be available cannot be predicted. The pressing need for a vaccine has prompted the trial of several candidate vaccines in people. The lessons learned from these trials will be valuable in future vaccine attempts.

Chemoprevention

Antiviral drugs also may be used to prevent infection. The ideal drugs for prevention block the early stages of viral infection, before the virus has a chance to convert its genetic material to DNA. To be

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effective, such drugs should be administered before exposure. Drugs taken at the time of exposure or shortly thereafter are unlikely to prevent infection altogether. The difference between a chemoprevention and vaccination is that the antiviral drugs must be present continually. Vaccines can be given once a year or less as the immune system provides the protection, not the material in the vaccine itself. In the absence of an effective vaccine, chemoprevention provides one of the only medical alternatives for protection of populations.

Chemoprevention is standard practice for two other diseases: malaria in people and heartworm in dogs. The required drugs used for prevention differ from those used for treatment. Chemopreventives are given to healthy people before they are infected. Consequently, the side effects of chemoprevention drugs must be minimal. The effects of chemopreventive drugs on the developing fetus as well as on people of marginal health and nutrition status must be evaluated.

A variety of antiviral drugs that may ultimately be suitable for use as chemopreventives is being developed. Drugs that interfere with early stages of infection, such as those that prevent binding of the virus to the cell or synthesis of viral DNA, should be effective. Drugs that are active against several of these steps are already being tested for efficacy in AIDS patients. For example, AZT prevents synthesis of viral DNA, and soluble CD4 prevents binding of the virus to the surface of the cell.

The side effects of drugs may be reduced by the use of combinations of compounds, each of which blocks a different step of virus replication. Rarely do drugs that act against different targets share common side effects. For this reason combinations of drugs may permit the use of substantially lower doses of individual components.

Preliminary experiments suggest that chemoprevention is a viable strategy for retroviruses. AZT is partially effective in reducing retrovirus infection of mice. The combination of AZT with another drug, interferon A, is efficient in preventing retrovirus infections in mice. AZT was also shown to prevent infections with the feline leukemia virus, another retrovirus. The details of infection by the mouse and cat retroviruses differ in some respects from those of infection with the AIDS virus or HIV infections of monkeys. For this reason, similar tests are now being conducted in an attempt to

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determine whether antiviral drugs can prevent HIV infection in monkeys.

Several populations are in dire need of effective medical prevention methods, including sex partners of HIV-1 infected people, newborns of HIV-1 infected mothers, and intravenous drug users. Health-care workers whose job requires invasive medical procedures of AIDS patients also require preventive measures. The infection rate in the urban areas of some countries is so high more than half of the adult population is at risk for HIV-1 infection. For example, the infection rates in some portions of the United States and central Africa range from 10 to 20 percent of the young adult population. Continual spread of the infection in these areas will have a catastrophic impact on the population.

It is possible that effective means of chemoprevention will develop within three or four years if we use a combination of drugs currently being evaluated in HIV-1 infected people. The ability of these drugs to prevent infection has been established both in animals and in people. However, the long-term health consequences of such treatment will not be known for many years.

* * *

The AIDS epidemic has arrived with unexpected violence. The true magnitude of this catastrophe is only now becoming apparent. We do not stand defenseless before this latest onslaught from the microbial world. Already we have harnessed our great scientific and medical heritage to the task of bringing this latest scourge under control. That the tools developed are not yet sufficient to cure or prevent infection reflects the complexity of the infection and disease as well as our overall understanding of the natural world. Had this epidemic arrived only one or two decades earlier, the progress made thus far would not have been possible.

Nonetheless, we have far to go before a cure or a vaccine will be found. Indeed, from our current vantage point, the road ahead seems much longer than the distance we have traveled. We must be prepared for a long haul. A consistent, steady application of science and medicine must be brought to bear. AIDS is a problem that is very likely to be with us for many decades. Knowledge of scientific and medical advances must be widely distributed. Access to the best

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diagnostic, treatment, and preventive measures should be distributed worldwide by the nations that have the resources to those which do not, for this is an epidemic that affects people everywhere. The control of this epidemic requires full use of our scientific, medical, social, and political resources.

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Living with AIDS

Dædalus
Spring 1989

Today we live with AIDS in much the same way as we live with thermonuclear weapons. Neither is likely soon to disappear from the scene. The question, then, becomes one of determining how the disease can be lived with.

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Norman E. Zinberg, M.D.

Social Policy: AIDS and Intravenous Drug Use

WITH EACH PASSING MONTH, as the human immunodeficiency virus (HIV)—the virus which leads to the acquired immune deficiency syndrome (AIDS)—continues to spread, it becomes clearer that social policy on AIDS cannot be considered apart from social policy on intravenous drug use (IVDU). Sharing intravenous needles is one means by which AIDS is transmitted. Although the numbers used to indicate the spread of HIV vary and are controversial, certain facts are clear. While the rate of spread of HIV among both homosexuals and bisexuals has dropped, transmission among intravenous drug users (IVDUs) has increased at a very high rate.

Furthermore, transmission among heterosexuals, and therefore among pregnant women, is occurring disproportionately in the minority communities of the unskilled and unemployed—the socially dispossessed.[1] This last point is crucial because illicit drug use, including IVDU, is highest within the same social groups.

The purpose of this paper is to spell out a new social policy for both illicit drug use and AIDS. To arrive at an effective program, I will first describe and analyze the dilemma inherent in our present policy positions. Next I will discuss the problems that must be confronted in determining policy changes. And finally I will recom-

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mend specific ways to deal with both drug use and the spread of the human immunodeficiency virus.

THE PRESENT POLICY DILEMMA

The various attempts being made to control both drug use and AIDS in our society reveal two conflicting approaches to these problems. The first is to help drug users follow their own life-style more safely, while the second is to attack this life-style. Although both concern using education to prevent the spread of HIV through sex and illicit drug use, these approaches would achieve this goal in different ways: the first is to advertise condoms for safer sex and explain how they may be used both homosexually and heterosexually, while the second is to include profamily messages in all educational efforts—messages that oppose unmarried sex, abortion, and homosexuality. The first approach differentiates between drugs in terms of their addiction potential and their capacity to lead to the spread of HIV and teaches how to use them (or any other kind of intoxicant, such as alcohol) in a controlled, responsible manner. The second approach considers all illicit drug use destructive and therefore makes no attempt to differentiate one illicit drug from another or their experimental use from their abuse. In addition, this second approach, though admitting that tobacco and alcohol may be dangerous, treats them with special deference. It also opposes any relaxation of the "Just say no" approach to illicit drug use, no matter how practical that relaxation might be—by, for example, decriminalizing the possession of small amounts of marijuana or teaching IVDUs to sterilize their needles.

Politicization

Many politicians, and certainly those in the New Right and conservative movements, have successfully adopted the second approach, that is, the profamily, "Just say no" position. It makes them appear to care about AIDS, social ills, and law and order without having to ask for large appropriations. Despite its pronouncements on drugs and their role in the spread of HIV, the Reagan administration asked for a reduction in the relatively small amounts of money already committed to the war on drugs, and it has not supported funding for addiction treatment.[2] In this case, paradoxically, those who generally oppose the New Right joined them in the antidrug frenzy, as did the

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Democrats in Congress during discussion of the antidrug-crusade bill in October 1986 and again in November 1988. Fighting illicit drugs is safe; there is a constituency for tobacco, for alcohol, and for guns, but none for drugs. Even the drug users do not vote their own preference. For more than a decade, such associations as the National Organization for the Reform of Marijuana Laws (NORML) have looked at the numbers—the 62 million Americans who have used marijuana, not to mention the 5 million or 6 million who have tried it within the past month—and have dreamed that these people would give political clout to their cause. But there has been no uprising by this group against the criminalization of drug use or the paucity of support for addiction treatment, even after the AIDS epidemic struck.

Consequently, protesting in support of drug users has been left either to an organization like NORML (a fringe group), or in the chilly hands of civil-liberty associations that struggle for principles without burning for the specific cause. A similar situation prevailed in regard to AIDS until publicity about the possible spread of the disease to the heterosexual community began to galvanize public opinion. Before that, if protests by gay-rights organizations were noticed at all, they were seen as giving politicians a chance to make some vague, tolerant response, followed by a moral, profamily statement. Under these circumstances it was easy for White House spokesmen such as Dr. Donald Ian Macdonald (director of the Drug Abuse Policy Office and special assistant to the president) to call for greater attention to the rights of the majority.[3] Thus, he and others were rallying those not involved in drug use or sexual deviance against those who were presumed to be a threat. Because there is so little political opposition to this stance, proving that such a threat exists is not even necessary.

Drug Use and AIDS

No rational connection exists between AIDS victims and drug users, with the important exception of IVDUs. Nevertheless, for several reasons AIDS and drug use have become linked in the public mind.

First, public statements about AIDS frequently list homosexual activity and IVDU as its leading causes. Second, many Americans, particularly the less sophisticated, believe that homosexual activity takes place in an atmosphere of lasciviousness where alcohol and other drugs are used with abandon. These notions center AIDS in a life-style that is unconventional and usually abhorrent. Third, the

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likelihood of a connection between drug use and AIDS was supported by an official White House spokesman, Dr. Carlton Turner. He held Dr. Macdonald's position earlier in the Reagan administration and was reported by *Newsweek* to have speculated that marijuana use could lead to homosexuality.[4] Fourth, Turner and other White House spokesmen have also referred to the old stepping-stone theory of drug use, which has been disproved many times but still retains currency. According to this theory, drug use is progressive: stronger and stronger drugs are needed to get the same effect, and thus users, no matter how mild their first drug, are bound to end up injecting heroin. This stepping-stone theory, which assumes that all or most drug users will eventually become IVDUs, strengthens the presumed linkage between drug use and AIDS.

PROBLEM AREAS IN POLICYMAKING

Has linking the spread of HIV with drug use penetrated the thinking of U.S. policymakers? Certainly our policymakers know the numbers, but knowing them is not the same thing as being fully aware that specific policies designed to prevent AIDS must take into consideration the historical and current social policies toward illicit drug use. For example, policymakers need to remember the decision to criminalize drug use and addiction, a decision embodied in the Harrison Narcotic Act of 1918 that was made about the same time England was deciding to treat drug use as a health problem.[5] The ramifications of the Harrison decision have dominated U.S. drug policy during the past seventy years and are crucial to the consideration of AIDS-prevention policies today.

The criminalization of illicit drug use in this country has resulted from a strong moral repugnance toward intoxication and from a hysterical fear that the use of such substances will destroy the moral fabric of American life. When moral fervor has been at a peak, draconian attempts to use criminal law to control drug consumption, such as the 1914 Volstead Act and the 1976 New York Rockefeller Drug Law, have led to disaster. The notion that increasing penalties act as deterrents dies hard. Witness the passage of the federal Anti-Drug Abuse Act of 1988, which raises the penalties above those of the already punishing 1986 bill, an obvious failure.

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The fact is that, whether because of or in spite of the wars on drugs, the use of intoxicants in the United States has been on a persistent decline since 1979.[6] The overall use of drugs has gone down, and the age of users has risen—a good sign, favoring control of compulsive use. This impressive drop has occurred only in the middle and upper middle classes, however. The use of drugs, particularly of hard liquor and cocaine, is still heavy in the low-skilled working class, the unemployed, and minority groups. (This has always been true of heroin.) The middle class is also responsible for the figures showing that during the past five years the sale of beer and light wines has overtaken the sale of hard liquor for the first time since 1934, when keeping such records began. While cocaine use has diminished in law firms, financial districts, sports, and the entertainment world, free-basing and the smoking of crack have proliferated in the South Bronx, East Los Angeles, and Roxbury. Not surprisingly, these are the same communities that show the highest and most rapidly rising rates of HIV positive.[7]

Social Setting

In my book *Drug, Set, and Setting*, I emphasize the importance of three variables in connection with the use of an intoxicant: the pharmacological properties of the drugs themselves; the set, that is, the attitudes and personality structure, of the user; and the influence of the physical and social setting in which use takes place.[8] Without knowledge of all three of these variables, we cannot identify the factors that affect the decision to use drugs. Nor can we predict the immediate impact of use on the individual or its eventual consequences.

Because the third variable, setting, has been least understood, the last chapter of the book pleads for its inclusion in future considerations of social policy. Unfortunately, this plea has not been heard. And now, just a few years later, when social policy questions of grave importance are again being considered, the alarmed public, still thinking (as it did in the mid-1960s) that drug use is the most serious domestic problem, is not paying any attention to the social setting in which use takes place.

Yet some vital changes in the setting have occurred since the 1960s. Alcohol and tobacco are now recognized as drugs. They differ from the other drugs in their pharmacological properties, but even more in

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their legal position. A moderate, humane policy toward both alcohol and tobacco use has been adopted that does take the social setting into account. Assaults on cigarette smoking, which is the most addictive habit (95 percent of users are addicts) and the most damaging to health (it causes 400,000 deaths per year), attempt to separate use from abuse.[9] Those who enjoy an occasional cigarette, pipe, or cigar in the proper quarters have not been interfered with, but the compulsive smoker is now required to observe special rules on airplanes and in public places. Actions taken against excessive alcohol consumption have followed a similar pattern. The 90 percent of drinkers who are controlled and follow regulations are not being interfered with. But striking changes have occurred in the public attitude toward drinking, particularly toward those who drive while intoxicated, with some states actually mandating treatment rather than punishment when no other violation is involved. Employee assistance programs are expanding and easing access to help for alcoholics, while the rise in the legal drinking age in most states is aimed at keeping alcohol out of the hands of young people. Thus in the areas of health care and the law, the public is attempting to distinguish between controlled and compulsive use of drugs.

Policy Failures

Current drug laws and treatment programs have failed to solve our drug problems. Addicts are regarded as lawbreakers, and they are expected to come to the ordinary institutional settings for help. If they are unable to do that, they are left on the streets to be dealt with by the criminal justice system. No legal effort has been made to distinguish use from abuse, and there is little concern about the health consequences of drug use.

The approach to AIDS has followed a parallel course. At first the public, including the very populations at risk, tried hard to ignore HIV, the virus that leads to the disease. The first effort to close the notorious San Francisco bathhouses led to a violent protest from the homosexual community, which saw this as both an assault on its civil liberties—for a time its legal efforts to prevent closure were joined by the American Civil Liberties Union (ACLU)—and as a sign of government discrimination. But as evidence accumulated, the attitudes of the homosexual community changed rapidly. This change and the influence of the social setting are amply demonstrated by the

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reduction in the rate of spread of HIV in San Francisco, where it is now down to 1 percent.

Whether the San Francisco homosexuals were entirely wrong in suspecting official discrimination remains in doubt. Certainly the official response to this disease at the beginning was slow and insufficient. Apparently, many citizens and officials simply wished that the condition would go away, and they put up with delays because those most affected—homosexuals and IVDUs—were social deviants. In fact, once awareness of the seriousness of the plague broke through, demands arose for the isolation and deportation of those affected. The debate about mandatory testing for HIV (similar to that concerning mandatory urine testing for illicit drug use) has been accompanied by calls for harsh legislation making it a crime to perform acts that could lead to transmission of HIV.[10]

A dreadful, painful death will come to those in the white, middle-class, and homosexual or bisexual groups that are already infected with HIV. But what will happen to social policy as it becomes increasingly clear that the group acquiring HIV-positive status radiates from IVDUs who are predominantly lower class and not white? It will be hard for the reigning majority to stop thinking of drug use with dread and users with hate—changes that will be necessary if significant social policy changes are to occur.

Here a curious irony emerges in regard to the minority communities. If a new social policy were to be adopted that not only made drug treatment available to all who could use it but also offered fresh, more effective treatment approaches, the minority communities would be the first to benefit. Yet these are the very communities that have been most obdurate about any relaxation of the war against drugs. In their daily, if not hourly, clashes with drug users, these communities have been most ravaged by the destruction of addiction: loss of life, crime, and property destruction are horribly familiar, while the promised program help has been sadly disappointing. These communities simply want drug use to go away, and they see any other aim, including new, experimental programs, as condoning drug use.

Spokespersons for these communities perceive our earlier drug policies as bearing out their fears. In 1972, when President Nixon appointed a "drug czar" to deal with the heroin epidemic and also supported the establishment of treatment centers—which, though

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widely advertised as multipurpose, were actually either methadone maintenance or concept houses (drug-free, live-in, community-oriented programs)—this move was popular in both the white and the black communities. The media ran uplifting stories about the successes of concept houses such as Synanon and Daytop Village, and other confrontational-style addiction-treatment centers. Vincent J. Dole (a professor and the senior physician at Rockefeller University and winner of the 1988 Lasker Award) had recently published his initial findings on methadone maintenance, showing the sharp reduction in crime, drug use, and destructive life-style that followed the use of methadone.[11] This buildup of treatment put graduates of treatment programs into employment and led to a drug-treatment industry filled with minority groups, as could be seen at the first few national methadone conferences, held between 1973 and 1976.

But then the soufflé began to fall. Although the number of addicts stabilized at a far higher level than before the epidemic, probably at about 500,000, it was clear by 1975 that the runaway increase had ended. Funds began to be cut, and the treatment system, which had been so rapidly expanded, deteriorated at equal speed. Problems had already come up earlier. Concept houses were good for some people, but their numbers were small. Methadone maintenance, while more effective for more people, was no magic bullet.[12] The argument raged over whether methadone was in essence a medicine that would permit rehabilitation, as Dole claimed, or whether it was just one drug that was being exchanged for another without making any real impact on addiction, as the drug-free advocates claimed. In either case, disappointment hung over the whole concept of treatment. Staffs were poorly paid; there was little or no incentive for new approaches. Because addicts travel poorly, clinics were situated in poor neighborhoods where this fractious, usually chronic, treatment population caused trouble and aroused opposition. It became impossible to find locations for new drug-treatment programs, so vociferous was community opposition. In 1981 when the Reagan administration shifted to block grants to the states rather than direct federal support, further weakening the funding, little concern was felt for any aspect of drug treatment.

Now that the specter of AIDS has appeared, interest in treatment has suddenly become enormous, but it lacks the freshness of 1972. Disillusionment continues, as do the old arguments. The failure of

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treatment programs is experienced, particularly by the minority communities, as a simple failure of drug treatment rather than as the broader failure of our short-sighted, inhumane, politically driven social policy. In fact, drug-treatment programs themselves have done fairly well despite their poorly trained staffs. Although drug-free houses had low retention rates, these were not zero. Methadone maintenance proved almost endlessly long, but a fair percentage of the people in this kind of program slowly moved toward social stability.[13] Considering the costs of other social agencies and of the criminal justice system, drug treatment has been extremely cost-effective. And much has been learned—a fact that should count for something.

Proposed Legalization of Illicit Drugs

Nothing better represents the tendency of social policy to swing back and forth between the call for total war on drug use and a rather casual interference with use than the current revival of proposals to make all drugs available and to regulate them according to the model of cigarettes and alcohol. In large measure, this stance results from the high cost of the war and its failure; in part, it is a reaction to its generally disruptive and inhumane character. The advocates of this position say little about its effect on the prevention of the spread of HIV and concentrate instead on the overall benefit of crime reduction and the freeing of society's resources for more constructive purposes, presumably including education.

In calling for the legalization of illicit drugs, the advocates of this proposal have not given serious consideration to the variables of drug, set, and setting. First, when it is a question of legalization, each drug must be dealt with separately because they all have different consequences in terms of toxicity and dependency. For example, despite the publicity that has been given to individual cases, deaths from cocaine caused by heart stoppage are rare; death resulting from heroin overdose is relatively common; and no deaths are known to have resulted from marijuana use.[14] The likelihood of dependency, or addiction, also varies enormously, ranging from 95 percent for cigarette smokers to 1 to 2 percent for marijuana users.[15] And the long-term health effects vary similarly.

Second, in view of the almost unrestricted availability of drugs that would accompany legalization, it would be virtually impossible for

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certain personality types to resist use and reuse. Therefore, at least in the first phase of legalization, use would greatly increase. Were it to include IVDU, particularly of cocaine, HIV would spread.

Third, because of the character of the social setting in which illicit drugs are used, legalization would result in an increase of casualties. This third variable—setting—embodies norms, sanctions, and rituals, which can encourage users to take intoxicants in a controlled and effective way rather than destructively. As recently as the 1960s and early 1970s, the development of social norms and sanctions sharply reduced the number of casualties from the use of LSD and other psychedelic drugs.[16] Today, however, the norms and sanctions that would encourage controlled use of cocaine and the opiates have not had an opportunity to develop—if, indeed, such moderating norms are possible for a drug as insidious as cocaine.

Finally, those who advocate discussing legalization—even the brilliant, articulate black mayor of Baltimore, Kurt Schmoke—do not stop to consider the struggle that might occur with the cultural majority, who today see all users of illicit drugs as enemy deviants, even though they have not yet made the emotional connection between drug use and AIDS. Were the proponents of any sort of legalization, perhaps of marijuana alone, to become active, a socially destructive struggle might ensue that would resemble the present fight over abortion.

Results of the War

The war against drugs has been almost totally unsuccessful on the so-called supply side. Drugs are coming into this country at an increasing rate despite the expenditure of hundreds of billions of dollars. Suppliers of marijuana, the bulkiest drug and therefore the easiest to interdict, have moved their production base to the United States; if air patrol becomes a problem, they simply shift operations indoors.[17] As proponents of legalization point out, law enforcement has kept up the price instead of reducing supply, thereby guaranteeing a monopoly and incredibly high profits to those who are willing to take the risks. Also, by keeping users deviant and outside the law, the war has spawned shooting galleries and crack houses, which spread HIV.

One could argue that keeping up the price has brought some success on the demand side. Perhaps some people who might have

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experimented and got into trouble have been unable to afford their drugs of choice. Nevertheless, availability is so great that almost anyone who wants to use drugs can do so. It is also true that some drug use has been prevented by negative attitudes toward use, either personal or social; but at the same time, the illicitness of the drugs interferes with the normal development of social sanctions and rituals. Despite earlier reports about the impact of the war on drugs and its acceleration, conditions have changed so much in the last three or four years that the new situation—the change in social class of much heavy drug use and actual addiction—must be recognized and taken into account.[18] Today, when a stepping-up of the war on drugs is being demanded, including the unprecedented use of the military and of mandatory urinalysis on the job, it looks as if the big guns are to be aimed at a socially excluded and politically underrepresented group of our population. Some of the proponents of the war, such as Congressman Charles Rangel of New York, are themselves the political representatives of these minority groups. Nevertheless, if this war heats up, it will not be just a war on drugs but a war mobilized by the majority, the franchised and the employed, against a minority—an essentially disenfranchised and deeply alienated segment of our society.

Here a clear parallel can be seen between the war against drugs and the effort to control the spread of HIV. For even while calling for a harder fight against AIDS, the public tends to support the moralist stance and to oppose any changes in social policy that would permit giving out free needles, setting up needle-exchange programs, or establishing experimental treatment programs. Apparently, the hope remains that if policies long shown to be ineffective are bolstered with fresh rhetoric and fervor, they will suddenly become effective. Nowhere is this attitude more evident than in the efforts at so-called education.

Education

From all quarters comes a call for increased education concerning both AIDS and illicit drug use. What is generally meant is *direct* education, that is, providing the facts in sex-education or drug-education courses. Yet, like the war on drugs, direct education, which has been promoted since 1962, has failed. Several studies have demonstrated that drug education, sometimes called value clarifica-

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tion or education in decision making, has usually resulted in an increase in drug use.[19] The common goal of these efforts has been the prevention of all use of illicit intoxicants. To my knowledge, no educational program has attempted to distinguish between use and abuse or to indicate that abuse may be avoided by means other than abstinence. Some of the presentations have been less fervid than others, but they have all inculcated the attitude that those who use any drugs at all, and of course those who get into trouble, are social deviants and destroyers of the moral fabric of society. The central spokesmen of most antidrug campaigns have been ex-addicts who describe the horror of their addiction and the terrible things they have done to support it. They point to themselves as proof that one should never use any drug, even once, because smoking a single marijuana joint can lead to heroin addiction.

This approach has its counterpart in the attitude toward AIDS. One of the first responses by the Moral Majority, and, indeed, by certain government representatives, was "Just say no" to sex. They demanded a return to premarital virginity and monogamous, heterosexual family life while they condemned the promotion of "safe sex" and condom use. Moreover, they strongly opposed any attempt to convince the public that condoms, though not infallible, would greatly reduce the chances of contracting HIV. This attitude contrasts strikingly with the situation in Great Britain, where a massive policy change has led to the dissemination of sterile needles.[20] There the use of condoms is recommended by placards posted at every airport and by announcements made openly and frequently on television, in both commercials and public-interest spots. Condoms are given away in dormitories, restrooms, and other public places. It is too early to say whether this education effort is succeeding, although a group in Liverpool, England, has described some favorable changes similar to those reported recently from San Francisco.[21] The British recognize that it is necessary to change public attitudes—to provide social learning that will shift values and make condom use acceptable, something that had been thought of as either unmanly or pleasure reducing.

In this country, on the other hand, every effort to use that sort of education has been either hampered or defeated. Here education campaigns have amounted to indirect attempts to promulgate social policy rather than dispense facts, and they have promoted the most

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simplistic moral and politically "correct" positions, whether about illicit drug use or AIDS. Only a few efforts have been made by the mass media to unveil the problems of HIV. Television programs, while stressing the horror of the disease, have nevertheless placed it in a romantic context: family members come together, forgive each other, and prove that love, though not a cure, can triumph over suffering. Direct sexual issues, such as promiscuity, the high incidence of transmission of HIV through anal intercourse, and the use of condoms, are rarely mentioned. Television programs on illicit drug use have a similar tone. For example, the goal of programs like "Forty-eight Hours on Crack Street" is to increase the viewers' perception that all drug use is bad, that all users are degenerates, and that we as a nation must rid ourselves of this plague. Obviously, the main effect of such programs is to make nonusers feel righteous and therefore resolved to intensify the war.

A question rarely asked is how such presentations affect drug users themselves—occasional users or addicts. The impact on occasional users is complex. Studies show that they are already concerned about controlling their drug use.[22] But far from leading them to abandon drugs, such programs increase their sense of having to hide the fact that they use them and to mouth the party line in public. Such a response stands in sharp contrast to the impact of drug use on a group—on a sports team, advertising agency, law firm, or stock brokerage establishment—when one of its members, a buddy, suddenly falls apart from addiction to cocaine. As for those addicts who come from the already dispossessed minorities, such "education" is further proof that they cannot hope for understanding from the institutions of the cultural majority, especially the law and the media. They can only become further alienated.

Treatment

One of the strongest indictments of our social policy toward both illicit drug users and people with AIDS is our low investment in treatment.[23] As the number of patients with AIDS increases and they become a greater burden on the health-care system, treatment planning is suffering from the same shortsighted niggardliness that has characterized drug-treatment programs.

Although it is true that treatment for illicit drug users works slowly, is much more often maintenance than cure, and frequently

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fails, it is by any count enormously cost-effective. Yet for years there has been a continuing reduction in public investment in treatment for all groups, and virtually no help from the public sector is available for cocaine users.[24] That lack can be partially explained by the recent transfer of such use from the middle to the lower class, which cannot afford private treatment. Yet now, when it is clear that destructive cocaine use, involving crack and intravenous dosing, is the chief drug-abuse problem in our society, treatment efforts are still paltry and poorly conceived.[25]

One reaction to the growing awareness that IVDUs are principally responsible for the spread of HIV to the heterosexual community is an increased demand for treatment. Despite the deadliness of this virus, the moral fervor that demands that treatment be done in the "right" way—that is, without condoning drug use—has restricted innovative programs that would offer users bleach, clean needles, or methadone. The answer to the claim that heroin addicts cannot be reached has been given by the San Francisco program, which sent outreach workers into the addict population with a single message: "Use bleach and stop the spread of AIDS."[26] Purposely avoiding references to treatment, abstinence, or morality, they delivered a straight health message, and it seems to be working. This approach contrasts sharply with those anti-AIDS programs that have attempted to induce IVDUs into a traditional treatment situation, thus implying that unless they conform to society's desires they will fail. These traditional programs attempt to combine a health message with the usual view of the reigning cultural majority—"We know what's best for you"—which completely undermines the anti-AIDS message. It is hard to imagine that people from the South Bronx, even those who think they want to stop use, will be willing to come into a system that seems to hate them. Treatment for addiction is not like treatment for pneumonia: it is the beginning of a process of social rehabilitation. But how can people reenter a social structure that views them as pariahs?

Although the San Francisco program and a few others like it indicate that heroin addicts are not so self-destructive and uneducable that they cannot be reached by anti-AIDS messages, the choice of treatment is not a simple decision for them. But even with apparently far-gone junkies, it is possible to discuss the pros and cons of treatment in general, as well as of specific programs. If such addicts

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decide to go into treatment, usually because of some overpowering necessity (trouble with the law, exhaustion after a drug run, pregnancy, or sometimes just feeling burned out), they make that decision carefully. Addicts' ideas about what they want and don't want are often chaotic and quixotic, closely related to fantasy, but still the result of social learning. And although addicts cling to many wild myths about drugs, their factual knowledge of the objective and subjective effects of the drugs they use is voluminous. With the occasional exception, they do not want to destroy themselves by contracting AIDS.[27] Instead—and this may sound fanciful—they feel like warriors, ready to go under rather than to move from the narrow territory they hold, which would mean succumbing to the obtuseness of the guardians of stereotypical virtue.

So far, only Tacoma, Washington, has had the nerve to run a needle-exchange program for addicts. One has been proposed for 400 addicts in New York City, but at this writing it was still not under way.[28] Unfortunately, the New York program will attract a group that has already been maximally exposed to HIV, and thus the program will not show results. Tacoma's program can get results, but its group is so small that it will be hard to tell whether these are significant. What is needed is programs in large cities that do not already have New York's high rate of seropositivity. Sadly, such efforts have been strongly opposed and caricatured as condoning drug use, despite preliminary reports from similar programs in Amsterdam[29] and Liverpool[30] indicating a reduction in the spread of seropositivity and no increase in drug use.

There is another curious irony associated with the dispensing of clean needles to addicts. An informal polling of methadone maintenance patients and of other IVDUs not in treatment, who might have been expected to favor such a program, has shown that they have very mixed feelings toward it. These IVDUs knew about AIDS and were fearful of it, but their own solution was to do away with drugs, meaning heroin.

Their paranoid attitude that "the government" did not care about them and was willing to let the drugs come in and kill them off reflected their wish for someone else to take the responsibility for their use. If drugs were cut off through the action of the powerful, they, in their helplessness, would not use drugs, but active, personal, internal restraint could not be expected of them. After conversing

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with a few of them, I saw something deeper in their fear of a sterile-needle program. To participate in such a program, particularly an exchange program, would require a degree of restraint, a degree of active struggle against their craving. And if they had that much capacity to restrain, why not more? Once the argument of total helplessness had been interfered with, they saw no reason why they would not be expected to go the whole way and stop altogether. Such an attitude is ambivalently held in this day of AIDS, but it remains strong and is not touched by rational drug education or AIDS education.

POLICY RECOMMENDATIONS

Several elements of our social policy must be changed if the spread of HIV is to be reduced and if destructive drug users are to receive treatment and rehabilitation. Innovative changes in the policies that we have embraced for so long are needed in the areas of education, treatment, and law enforcement. As is indicated by the Anti-Drug Abuse Law of 1988, the political process has been excruciatingly slow to take into account the direct relationship between IVDU and AIDS.

Education

Not one but several prevention campaigns need to be launched. They must have in common a clarity of purpose and a hardheaded pragmatism concerning the problems that must be prevented. All programs should have as their top priority the reduction of the spread of HIV. That is, the drug and AIDS issues should be seen as serious health problems, and moral and criminal justice issues should take second place. My proposal amounts to a national educational effort that would be aimed at everyone, similar to those already launched in Great Britain, Sweden, and the Netherlands. Because the United States has a more diverse population than these countries, our programs must be targeted at a variety of groups. Small disagreements, such as the question of whether to use only English or to acknowledge minority use of other languages, should not be allowed to get in the way. People must be reached by every means possible.

The education campaign I have in mind is not new. Much of it, in fact, is implicit in the recommendations made in 1988 by the

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Presidential Commission on AIDS headed by Admiral James D. Watkins. That report followed the lead of other reports on drug use, such as those of the National Commission on Marihuana and Drug Abuse (the Shafer Commission) of 1972–1973,[31] the National Commission on Mental Health of 1978,[32] and in 1982 the report of a study by the Committee of the Institute on Medicine of the Division of Health Sciences Policy entitled *Marijuana and Health* (the Relman Report).[33] All these committees, composed of people who could never be accused of condoning drug use, raised questions about the war on drugs. All recommended considering drug problems more from the perspective of health than from one of morality or criminal justice. All have advocated an education campaign based on promoting good health. And all were virtually ignored by President Reagan and by other prominent political figures. (President Nixon actually rejected Governor Shafer's report, which is now seen as a model of what a commission can do.) What a new campaign needs in order to succeed is the political commitment of the administration and other key political leaders.

The elements of the new campaign are simple. IVDUs and those suffering from AIDS experience themselves as dispossessed and alienated from ordinary society. They are unlikely to be reached by a recitation of numbers, the printed word, or data on the small screen, and they mistrust the messages sent from "official" sources. These groups can best be reached by indigenous outreach workers, who should move in with a single message: "This is how you keep from getting and spreading AIDS." The important thing is what is not said, for such educators are not there to reform life-styles. The campaign in San Francisco that has followed this principle seems to be working.[34] The one in Baltimore that has attempted to get addicts into treatment, that is, to reform them, has been evaluated as a failure.[35]

For our culture as a whole, education campaigns should promulgate the same health messages in a more complex way. They should include explicit discussion of the function of condoms, of what sexual practices are most likely to transmit AIDS, and of what kinds of drug use lead to the spread of HIV.

Although I believe that the material for such a campaign is already available in the existing learned commission reports, another such report may be needed. Preparing it would consume valuable time, however, and it should not be undertaken without a well-publicized

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political agreement that its recommendations will be implemented. There is little question about the findings. In the same way, most workers in the field knew what the National AIDS Commission would find once its members had agreed to do a serious piece of work.

Treatment

Above all, we must increase treatment capacity for both IVDUs and AIDS victims. We must improve access to treatment, and train and pay superior personnel. To make access easier, long waiting lists must be eliminated, and new outreach efforts made. Making outreach a crucial part of the program would contribute greatly to more effective treatment.

Sterile needles should be given away with the fewest possible strings attached. Data from England[36] and the Netherlands[37] indicate that not only does providing needles *not* increase use or even seem to condone use, but participating in a needle-exchange program may lead those who take this first step to become engaged in the larger social system and eventually to seek treatment. Rapid action is needed in this area, for HIV-positive rates are soaring in minority communities. Rates among black IVDUs in the South Bronx, and presumably among their sexual partners, approach 60 percent; among Hispanic IVDUs, 40 percent; and among white IVDUs in the North Bronx, 20 percent.[38] In the same way, methadone should be supplied on demand. Any procedure that will engage addicts and wean them away from their resentful isolation should be encouraged. Equally important, the public must be willing to support reasonable salaries and a high level of training for the personnel manning such sensitive spots. If these crucial contacts are left in the hands of untrained and inexperienced people, the programs will fail. Training centers need to be established as quickly as possible in order to provide the needed personnel.

In the past, intravenous heroin users have been the main group to test HIV positive. But now intravenous cocaine use is increasing rapidly among former users of cocaine itself or of cocaine in crack form.[39] This group, in contrast to the aging population of heroin addicts, is young and very active sexually, and therefore it is more at risk. Because there has been nothing like methadone to bring cocaine IVDUs into a treatment setting, they will be harder to reach and to maintain contact with. And the recent history of middle-class cocaine

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use has shown the difficulty of continuing to use that stimulant drug without also using a balancing, restraining drug such as alcohol or a tranquilizer. Finally, this new, more impulsive crowd could easily turn to heroin, fueling a new cycle of addiction and a further threat of spreading HIV.

Excellent models already exist for outreach programs. Since 1981, Massachusetts has sponsored the Family Continuity Program (FCP), designed to involve and treat multiproblem, hard-to-reach families. It was clear at the beginning that almost every family in this program would have serious drug and alcohol problems, as well as problems such as incest. Reflecting the ills of society as these families do, they also frequently contain members who are HIV positive or who have AIDS. Before such families are referred to FCP, they have tried several other public agencies without success: missed appointments, failed plans, police and court entanglements have been the rule. FCP selects workers carefully and trains them to go out and work on the clients' own turf. They take over cases completely, thus forcing clients to deal with FCP workers only instead of with a maze of health-care social workers and court officers. To involve people so lost and bruised in a consistent treatment program requires skill and patience—great patience. But this sort of program can work, and it is cost-effective.[40] It limits the clients' contacts to one agency rather than many, and early case findings in many health-care areas, including addiction and testing HIV positive, reduce the chaos produced in the health-care system by referrals of those who are already severely, chronically, and expensively ill.

In dealing with addicts, outreach workers must have more to offer than the simplistic advice to "get treated and straighten out." They should be able to lend a sympathetic hand if the drug users try to reenter society—a society that should put deeds behind words by arranging special educational opportunities, a job corps, and programs in physical care and rehabilitation. Such ideas also are not new. In 1971 the Vera Institute of Justice developed a supported work program that included many of those notions and was very successful. Vera recognized that, unlike alcoholism, which characteristically develops later in life after its sufferers have had a chance to learn some skills to which they may return, drug addiction starts early. Addicts may have had little opportunity to acquire skills or even to learn how to work, to be on time, or to communicate with

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others. The Vera program was devised to meet the client where the client was, and with what we know now we could be even more successful in such educational efforts.[41]

Law Enforcement

My recommendations do not exclude law-enforcement efforts. In fact, I reject the proposal to legalize all illicit drugs and advocate a more coherent, consistent effort at enforcement and sentencing. Both James Q. Wilson (a professor of political science at Stanford University) and John Kaplan (a professor of law at Stanford Law School)[42] have emphasized the capacity of law enforcement to reengage people with the social system *when* enforcement is fair, swift, and effective. In a substantial percentage of people arrested for other than drug-related crimes, heroin, cocaine, and occasionally PCP have been found in their urine. This finding indicates that the level of interaction between the use of these drugs and the commission of other crimes is high. The interaction itself is no surprise, but the high rates are—72 percent in the District of Columbia, 68 percent in New York, and 67 percent in Los Angeles, an overall average in the large cities of 70 percent. The so-called J-curve, which shows that a small percentage of the clients of any health-care system uses a high percentage of the services, is likely to operate here too, so that a small percentage of users will commit a high percentage of the crimes. Regular urine testing of violators, assuming that it is for cause and therefore legal, would have a place during pretrial periods and certainly during any probationary period. Years ago George Vaillant,[43] in his studies of people released from U.S. Public Health Service hospitals, concluded that enforced parole is the best way to keep people in treatment. John Kaplan, noting the overcrowding of the penal system and its poor record, suggests a short but sure incarceration as the penalty for dirty urine.[44]

An enforcement approach that emphasizes coerced abstinence is not so different from treatment as it might sound. Methadone, for example, acts as a form of coercion in methadone maintenance, and the drug-free programs are well known for their heavy-handed approach to clients. In an odd way, coercion in the treatment of drug abusers makes theoretical sense, even though it does not make sense in most other treatment situations. In contrast to alcohol users, who can get their drug anywhere, illicit drug abusers take a certain pride

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in their ability to hustle, survive, and keep up their habit on the street. They cohere around what Erik Erikson calls a negative identity,[45] and whatever self-esteem they can muster is invested in this antisocial know-how. This source of self-esteem often prevents them from tamely submitting to the dictates of the reigning culture. They hate to admit that they cannot or do not want to hack it on the street any more; they experience giving in and asking for help as weakness or degradation. Hence, being coerced into treatment allows them to save face. Hearing "I wouldn't be here if I didn't have to" enables the program person to respond, "Of course not, but as long as you're stuck here, let's see what we can do." Such a stance works in the criminal justice system as well, but it requires greater effort.

* * *

Educating the majority to a more humane and pragmatic approach based on the principles of good health, offering better access to drug treatment (including outreach programs), and coordinating these measures with swift, effective law enforcement—these are the elements of a social policy that could deal constructively with the drug problem. This policy would not win the war and suddenly make drug use or AIDS go away, but it would go a long way toward reaching the population most at risk for testing HIV positive. Nothing will do that. But it is a workable plan that is neither a surrender to unfettered drug abuse nor just a repetition of an old policy that has not worked.

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John H. Gagnon

Disease and Desire

MAKING SATISFACTORY PREDICTIONS ABOUT the short- and long-term impact of HIV disease on sexual life in the United States would require substantive knowledge about both the "change agent" and the domain of social practice that the change agent affects. Neither of these factors is well understood now, either empirically or theoretically. This is not to say that we do not know a great deal about the virus. Intense effort and vast expenditures are going into the attempt to understand the virus and the immune system, to develop chemoprophylaxis for those who are ill, and to discover vaccines to prevent the further spread of the disease.[1] However, our data on the numbers of persons who are infected with the virus, the frequency of the forms of conduct that spread the disease, the differential efficiency of transmission by any of these activities, and the variability of the latency period still do not allow us to make a definitive statement about the natural course of the disease and its epidemiology in the population of the United States.[2]

The figure on the numbers of persons who are HIV positive and the sensitivity of these figures to the manipulation of the variables that are used to estimate them is an important example of this indeterminacy. The Coolfont report estimate that from 1 million to 1.5 million persons had been infected with HIV was based on speculative arithmetic.[3] That the Domestic Policy Council reported a similar figure some three years later, after a certain amount of admittedly limited research,[4] suggests that the advances we have

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made in grasping the dimensions of the epidemic are still modest. Estimating the number of persons infected from the numbers of persons who have AIDS rests on several factors: estimates of the latency period, the accuracy of the AIDS reporting system, deaths associated with having HIV disease before it was defined as AIDS, as well as estimates of the number of men who have sex with men and the number of needle-sharing IVDUs in each AIDS locale. Conflict in New York City over revised estimates of the number of men who have sex with men suggests the complexity of this task.[5]

If we are to make some sense of the impact of HIV on sexual practice in the middle term (say ten years), we must make some assumptions about the shape of the epidemic up to this point and prophesy what it will eventually look like. With the evidence we have now, it is possible to characterize the transmission characteristics of HIV in the United States in the following way: HIV disease appears to be difficult to transmit except through blood-blood or semen-blood contact. Even in these circumstances the chance of transmission is low (far lower, for instance, than for the transmission of the hepatitis virus). In the vast majority of the diagnosed cases of AIDS and HIV transmission in the United States and Europe, frequent anal intercourse and needle sharing associated with intravenous drug use can be identified as the primary means of transmission. Blood-blood transmission via contaminated blood products accounts for the infection of transfusees and hemophiliacs. There are some cases of transmission among health-care workers through needle sticks. In a far smaller number of cases there is heterosexual transmission through vaginal intercourse of an infected person with a regular sexual partner. The degree to which other cofactors are influential in the transmission via vaginal intercourse in the United States have not yet received definitive study (degree of infectiousness of the sexual partner as measured by stage of disease, prior or current infection with sexually transmitted diseases that may make transmission more efficient, lack of circumcision of the male partner, and other as yet unknown attributes of the uninfected partner).

If HIV disease remains what we observe it to be now—a disease that is relatively hard to transmit, that requires certain sexual practices for sexual transmission, and that afflicts primarily men who have sex with men and minority group members via sexual contacts with intravenous drug users who share needles—then it will have one

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sort of impact on sexual practice in our society. If on the other hand there is another, still secret HIV epidemic concealed from us by very long latency times or through spread into previously uninfected groups that are not being well monitored and who will appear with the disease seven to eight years from now, then it will have another sort of impact. We do not currently have evidence of an imminent wildfire epidemic among heterosexuals, regardless of what segment of the society they represent. If such an epidemic is in the offing, it will occur some years into the 1990s and a new scenario will have to be written for the change agent and its impact on sexual life in the United States.

RESEARCH AND REPRESENTATION

It is difficult to characterize the nature of the change agent for reasons other than incomplete scientific evidence. The way in which the collective representations of the epidemic (as distinct from the epidemic itself) have evolved is another reason. Most of our society comes in contact with the epidemic indirectly, through its representation in the mass media, which both report and reshape the scientific evidence. Only some of us know people in our extended social networks who have HIV disease.[6] Even fewer of us have close friends or lovers who are HIV positive or have AIDS. A still smaller number of us receive salaries or other gratuities to work directly on the AIDS epidemic, though this number may perhaps approach the number of new cases of AIDS in any year. Even persons with AIDS are widely split into different social groups.

In the present dominant representation of the sexual dimensions of the epidemic, the emphasis is on the dangers of multiple sexual contacts and of sexual contact with those in high-risk groups and those who are HIV positive or who have overt AIDS. In this view the use of certain sexual techniques and of condoms and other safe-sex practices, including abstinence, are promoted. (Certain high-risk groups are usually identified—gay and bisexual men and intravenous drug users—though we are assured that there are no high-risk groups, only high-risk practices.) Also considered to be at risk are those who are in the sexually active periods of their lives or who are regularly sexually active with multiple partners: adolescents, young adults prior to marriage, persons who are uncoupled later in life,

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women and men in the sex industry, persons having sex outside marriage, and until recently clients of women in the sexual industry. The image ranges from one of low-level danger of infection with "an invariably fatal disease" for most persons to acute danger for those with a "fast track" sexual life. In addition, risks such as the use of alcohol and drugs, which decrease prudential behavior, are cautioned against and the possible cofactors of other sexually transmitted diseases are noted but not emphasized. It is this representation of the sexual dimensions of the epidemic that will have an impact on the sexual practices of most persons in the society in the short term.

It would be fairly easy to measure the impact of both the epidemic as it is and the epidemic as it is represented if we had baseline data with which to measure change in sexual practice. If we knew what the sexual practices of various groups in the society were and had explanations for why persons conduct themselves in certain ways, we could employ the usual methods of social science to monitor how behavior changes as both the epidemic and its representations change.

Both the baseline data needed and adequate theories of sexual conduct, however, are in short supply.[7] To point out that the data gathered by the Kinsey group are between forty and fifty years old is now commonplace, yet they were used in the absence of other observations to estimate various sexual parameters relevant to the natural course of the disease as well as its epidemiology.[8] Already when these data were collected, persons of some methodological sophistication were recognizing the limitations of using these observations for such purposes.[9] At the same time the Kinsey studies did open up the area of sex research and offer a number of directions for work over the next decades.

The sex-research agenda that dominated the period from Kinsey to the onset of the AIDS epidemic was primarily driven either by the social problems associated with sexuality or by the mass-media interest in various sexual practices. The scientific investigation of this period concerned the virginity and fertility of young people (primarily of young women), the changing lives of gay men and lesbians, the impact of erotica and pornography (particularly after the early 1960s), the identification and treatment of sexual dysfunctions (after 1964), and sexual violence and sexual abuse (after 1975).[10] The mass media were interested in reporting findings about these matters as

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well as in generating advice about sexuality, particularly for women —about such topics as the female orgasm, sexual dysfunction, sexual technique, and maintaining relationships with men. Men were also being advised, but the advice was being packaged in somewhat different ways (contrast *Playboy* with *McCall's* treatment of these subjects). While research was also done on sex offenders, female prostitution, sexually transmitted diseases, extramarital sex, and masturbation, it was more intermittent and fragmented.

This was the small body of sex research that existed in 1980. Once they saw that the AIDS epidemic had a major sexual dimension, people nearly immediately recognized that this data base was inadequate. As the new AIDS-driven research agenda has evolved, it has been discovered that there are a distressing number of empty or near-empty files that need to be filled, that there are others that have to be relabeled, and that many new files have to be made up and filled. Depending on the duration and extent of the epidemic, the new agenda for sex research set by the epidemic will contribute to society's representation of sexuality.

As the epidemic has evolved, the targets of research interest have shifted from the spread of the disease through various social groups to the expectations of where the disease may spread next. The focus and intensity of research vary as the estimate of the potential for spread outside the currently infected groups grows and as effective political groups make successful claims on the AIDS dollars. Thus, the level of research interest rises and falls as groups are identified as more or less at risk and appear to endanger "the general population," "the heterosexual community," and "those currently at lower risk."

AIDS AND GAY MEN

Since the disease was first identified in members of gay communities in large cities, the first sets of questions about sexual conduct focused on this group. Was it what these men were doing sexually that spread the disease? And if the disease were spread by sexual contact, what elements of their sex lives were critical to transmission? Given how little was known and how esoteric the gay community appeared to most investigators, nearly everything was suspect, including the brands of lubricants used in sexual relations, the drugs that enhanced sexual arousal, and the specific sexual techniques that were common

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practice.[11] As the epidemiological search among gay men identified certain sexual practices as potential routes of transmission and since numbers of sexual partners appeared to increase the likelihood of infection, concern about changing these forms of conduct grew.

As an attempt was being made to fit what was being learned from epidemiological studies of the disease in a few major urban centers into a set of larger understandings about men who had sex with men, it became clear that even the most basic information was lacking. While the Kinsey estimates of the numbers of men who had sex with men were widely disseminated (more than a third of men, 10 percent having sex with men exclusively for three years and 4 percent having sex only with men up to the time of the interview) and the belief that one man in ten was exclusively or nearly exclusively homosexual was widely held in the gay community, these were not scientifically robust estimates.[12] In the absence of a satisfactory sample survey in which individuals could safely disclose a sexual preference that was against the law, no accurate figure was available.

In addition, the social, psychological, and cultural world of those labeled homosexual underwent profound transformation from the early 1950s to the 1980s.[13] In part, this transformation depended on other groups questioning authority: black liberationists, the civil-rights movement, the various phases of youth revolt from 1964 to the mid-1970s, the women's movement, and environmentalists were all part of the ferment in which gay liberation flourished. It is not clear the degree to which social science research during this period contributed to these developments, though the language challenging the tenets of psychoanalysis, which had provided the medical justification for homosexual perversity, came from a general sociological challenge to such theories of individual deviance.[14] Homosexuality was socially constructed, reported the social scientists, lived out in ways that were determined by culture and history rather than by biological factors or early warpings of the personality. Whatever psychological difficulties gay men and lesbians might have, they were the consequences of oppression (later "homophobia"), according to the scientists, rather than the pathologies thought to be associated with same-gender desire.

By the early 1970s, a number of community studies based on convenience samples and ethnographies had been conducted that chronicle the development of gay male and lesbian life-styles in the

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great cities of the United States.[15] This was a community that had been transformed from what was primarily a sexual marketplace in the 1950s to full-fledged cultural communities, somewhat separate for men and women, with their own politics, commercial institutions, cultural life, and housing patterns—communities that had developed quite new relations, at least in some cities, between themselves and the larger communities in which they were embedded. During the 1970s, the research momentum faltered and the intellectual and scientific understandings of these communities were largely transferred to what were previously the "objects" of heterosexual inquiry. In this new research climate, gay scientists and intellectuals began a research agenda in sociology, psychology, history, and even psychoanalysis.

Central to the development of this new community and identity was an openness of sexual expression and a new cult of manliness. It appears that numbers of sexual partners increased (though convenience-sample data from the late 1960s and early 1970s, as well as the original Kinsey interviews with men who nearly exclusively had sex with men, suggest that having many sexual partners was not uncommon in earlier generations). The incidence, frequency, and reciprocity in anal sex increased. The institutions of this sexually liberated group offered a kind of sexual life for many men who had previously lived lives of emotional and sexual repression. The cities in which these new institutions operated most openly became national and regional meccas for gay men. They migrated to or vacationed in such cities as New York, Los Angeles, San Francisco, Houston, and Miami.[16]

The difficulty certain political leaders and segments of the gay community had in recognizing the dangers of the AIDS epidemic rested at least in part on the important role that sexual liberation had played in personal and political liberation. Those promoting a "safer" sexual life that seemed consonant with the gravity of the AIDS epidemic often did not recognize that the price being paid for changes in sexual behavior was more than sexual pleasure, important as that was.[17] Safer sex was, at least for *some* groups and individuals and in the early stages of the epidemic, a repudiation of a cultural norm embedded in a nascent community. Less visible but coexisting with these norms was another life-style—a conception of gay life as one of permanent couples. Modeled on the notion of the faithful,

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emotionally constant couple recommended to heterosexuals, the male couple represented an alternative to the more intensely sexual life-style of multiple casual partners.[18]

This alternative life-style has now become recommended as part of gay life in the United States. Dating rather than "cruising," affectionate relationships as well as or in place of "hot" sexual contacts, and socializing in friendship circles rather than in bars are aspects of the preferred if not always dominant gay male life-style. An increase in this pattern (which has always existed among men who have sex with men) was already observable in the early 1980s and has been accelerated in the epicenters of the epidemic by the severe toll the disease has taken. This is also a pattern that is characteristic of men at a later stage in life, however. Like the rest of the baby-boom generation, the gay male community is an aging one.

We do not know how deeply these changes in sexual conduct have penetrated the lives of young persons beginning to participate in gay life at present or how characteristic the practice of safer sex is outside the urban centers of the epidemic. Whether microepidemics have begun in other communities is also unknown, though it is knowable through research.

All this is particularly important to know in the cultural and geographical communities that are outside the main centers in which research has been conducted. We do not know what the situation is for men in minority and working-class communities who have sex only with men, and the extent of the spread of HIV disease in such cities as Houston, New Orleans, Detroit, Denver, and Tucson remains a mystery except as indexed by reported cases of AIDS. At this time research has been conducted on white male, moderately well-educated gay communities. Everyone and everywhere else is *terra obscura.*

What is apparent is that gay life has sustained itself and that new social forms have been created to sustain the connectivity of the community life. Working on the epidemic has become the focus of many persons in the gay community. Volunteering and political action are widespread, as is caring for the sick and dying through friendship networks. The public manifestations of sex are more muted. There are many persons now in couples who probably would not have been a decade ago, or at least not so constantly in couples.

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About half the gay men in the epicenters of the epidemic between thirty and forty-five are HIV positive.[19] We do not know how many men who are younger or older than this group are HIV positive. It is clear, however, that substantial numbers of young persons are entering the gay community with no experience of AIDS except seeing it among their older friends. It is also clear that the HIV virus is now well seeded in these communities and that safer sexual practices will have to continue for many decades.

The future of gay male sexuality is deeply entangled with the more complex issues of gay male identity and gay male culture. Illness and death from AIDS is very much present in the consciousness of even the youngest gay men. The cultural movement toward the life-style of couples (what Martin Levine has called the heterosexualization of gay desire) appears to be widespread.[20] The gay press and other gay cultural institutions support safe sex and disease-proof life-styles at the individual and community levels. The gay population, at least in the epicenters of the epidemic, seems to have adapted to the realization that HIV is endemic to its community.

What has been learned from the experience of gay men and AIDS is quite complex. From research based on AIDS, very little has been learned about same-gender sexual desire and the social and psychological complexity of the lives of gay men. Narrow disease-focused epidemiological studies have not contributed to a basic understanding of men who have sex with men. However, new knowledge has come from the ways in which the new gay male identity was formed in the context of sexual freedom and the rapidity with which that identity was transformed by the AIDS epidemic. The flexibility and openness to change that have characterized individuals in the gay male community may give us the most instructive information about the nature of sexuality as an element responsive to culture and context rather than something fixed and immutable. That all these sexual changes occurred in the context of community support indicates the importance of social connectivity in maintaining and changing sexual conduct.

THE BISEXUAL BRIDGE

Among the first concerns expressed after the extent of the epidemic had been identified among gay men was the potential for spread of

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the disease from that population to the population of heterosexuals through bisexuality, having sex with both men and women. The concern about transmission induced the usual epidemiological questions: How many bisexuals were there? With whom did they have sex? How many bisexuals were currently infected? Did they use the sexual techniques that had been identified as risky?

Such questions quickly melded into a concern about behavior change: How could bisexual groups be identified? Were there different channels of education that needed to be accessed for different groups of bisexuals? How secret were their practices, and how difficult would it be to locate such persons? Some investigators worried that even with universal testing of blood donations, this collection of individuals might pose a special danger to the blood supply.

Earlier work offered only limited directions: the files were largely empty and arranged in somewhat unhelpful ways. On the other hand there were indications that the term *bisexual* might be too homogenizing. Clinical and criminological studies had early identified a variety of persons who had sex with both men and women but whose conduct seemed unlike what was described in the language of psychoanalysis as typical of true, obligatory, or exclusive homosexuals.

In contrast, Kinsey treated bisexuals as unproblematic. He saw them simply as persons who had sex with both men and women and considered their conduct well within the biological potential for sexual action.[21] From this perspective, bisexual conduct did not seem to express some underlying pathology or personality type, though there were social contexts or periods in the life course when a mixture of same- or opposite-gender sexual partners appeared more likely.

Later ethnographic work and interviews with convenience samples of various kinds (that is, unsystematic collections of volunteers) identified a very wide variety of persons as having had sex with both men and women as a result of their social and cultural contexts. A number of investigators identified a group of young men who for money or gifts had sex with older men.[22] Some of these young men were delinquents; others were in military service and away from home; others were down on their luck. All had sexual relationships with young women. The investigators found other young men, including those who had sex with young women as well as those whose sexual desires were more exclusively directed toward men,

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operating in the world of male prostitution—selling themselves on a regular basis to other men and living in a demi-monde marginal to the more conventional world around them. This was a complex world involving a system of prostitution not unlike that of female prostitutes—prostitution on the street, in bars, on the phone; call boys and male companions who were supported like mistresses. Unlike these groups were the male prisoners who had sex with other incarcerated men. Here the mixture of motives was certainly as complex as similar patterns in the community. For many men, sex in prison with men was simply a surrogate for sex with women in the free world and often met the same psychological need for dominance and control.[23]

In addition to these groups of men there was still another that was far more difficult to study: conventional men with entirely secretive sexual lives with other men. This included those who were married and had families but had anonymous sex with other men in public places (baths, parks, public toilets).[24] These men did not participate in the homosexual community except when out of town and only then as sexual transients. Such men surfaced on the police blotter and in little scandals that broke up families or resulted in therapeutic interventions. In more recent times at least some of these men have worked out new adjustments—some joining the gay community while attempting to continue relations with their former wives and children. Few studies of this population exist, and while it is suspected to exist in minority communities as well as among the white majority, it is only on white males that research has been conducted.

During the late 1960s concern about bisexuals as a potential new social type appeared in the literature.[25] Some persons who had had sex with both men and women reported that they had done so because they enjoyed sex with people of both genders and because the satisfactions they received from one sex were not equivalent to those they received from the other. In the sexually experimental climate of the times, bisexuality became a way for some to try out several identities. These persons argued that their interest in sex with people of both genders was not a way station from heterosexuality to homosexuality or from homosexuality to heterosexuality. As large numbers of gay men and lesbians were interviewed in the early and mid-1970s, it became evident that substantial proportions of these

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groups had been married and that many (particularly lesbians) were raising children. Bisexuality was becoming one of the increasing possibilities of sexual adjustment. The research literature of the period began to depict these new patterns as the development of new sociosexual identities in a changing world.

With the onset of the AIDS epidemic, bisexual men who were having sex with men very quickly became identified as a potential bridge for infection from the gay male community. Given this early concern, it is not clear why research on bisexual transmission has been so spotty. A study of women with known partners who had sex with men, based on a variety of case-collection methods (newspaper advertisements, notices in sexually transmitted disease clinics, friends of friends), was initiated in California and still continues as a research and education effort.[26] It was this study that early identified seroconversions among women who had had anal sex with partners who had had sex with other men. In the cohort studies of gay men, undertaken to determine the rates of seroconversion, specialized studies have not been conducted on men having sex with both men and women. One study of black men in San Francisco reporting sexual experience with both men and women is in its early stages.[27] None of these studies has been undertaken to understand sexual phenomena but, rather, to measure the risk of seroconversion and the effectiveness of prevention efforts. Such purely AIDS-driven work does not provide any estimate of the numbers in any population group who are having sex with both women and men and forces researchers to follow outbreaks of the epidemic rather than to anticipate its course.

As the AIDS epidemic has evolved, two additional patterns of bisexuality have become especially salient. While these have been noted in minority communities in the United States, the patterns are not unique to these communities. One pattern is based on a larger cultural pattern in which gender divisions are profound and in which men who prefer to have sex with men are socially defined as women in men's bodies. This pattern is common in Latin America and many regions of the Mediterranean basin. In this culture (now including some U.S. groups of Hispanic origin), a man who has sex with women is a man, a man who has sex with men (who inserts his penis in a male partner) remains a man, but the man who is receptive is socially defined as a woman. The inserter (the "activo") is a man; the insertee (the "passivo") is a woman.[28] The complex of general

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cultural values is the frame for this kind of bisexuality, and other social groups in the United States share it. Since such men do not think of themselves as homosexuals, they are not accessible to programs of behavior change aimed at gay men.

If this pattern is based on an accentuated difference between women and men, the second pattern is based on minimizing the distinctions between the objects of desire and increasing the importance of the impulse. This is a pattern the research subjects have described as "messing around." While this pattern has been recently identified among some black men, it also appears in other groups of men as well (particularly when they are in all-male contexts).

There is an indifference to the gender of the sexual partner under various conditions, which include drinking, drug use, and feeling sexually aroused after an evening of unsuccessful sexual pursuit or when sexual pursuit is restricted by fatigue, lack of time, or income. Women are preferred, but men are acceptable under certain conditions. "Getting your rocks off" or "getting your ashes hauled" is traditional male argot for sexual contacts which do not involve affective involvement and which are motivated by a desire indifferent to its object. In these circumstances the form that questions might take in eliciting information about such experiences from men is fairly ambiguous.

Bisexuality represents as serious a scientific problem to the sex research driven by the AIDS epidemic as it did to sex research from psychoanalysis onward. It resists being easily categorized so that one cannot develop a singular protocol either for the study of disease transmission or for the control of the disease. As a consequence, the various types of diverse conduct that are covered by the label will be of interest only so long as they appear to have some relevance to the control of disease spread. If there does not appear to be any major risk of transmission to those who are currently uninfected in a specific bisexual subgroup (e.g., hustlers, prisoners, closeted men, activos), research concern with that subgroup will disappear. If on the other hand such behavior turns out to be important in the spread to the currently uninfected, efforts at funding and control will increase, but probably in fairly clumsy ways exactly because of the social and cultural diversity of these subgroups.

Nearly all these forms of bisexuality have a future. Only a few appear to be particularly important in disease transmission (though

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this impression may rest more on scientific ignorance than evidence) and these result from the use of sexual techniques that have been responsible for transmission primarily among gay men. Thus, the youth who provide receptive anal sex for pay or gifts (now often runaways or throwaway children), the married men who have closeted sexual lives with other men, activos in the Hispanic community, and men who just "mess around" may be potential bridges to other sexual partners. If transmission is more efficient in frequent passive anal intercourse, then it is the first of these groups that is particularly at risk.

FEMALE PROSTITUTION

The possibility that women who have sex with men for pay might transmit the HIV virus was recognized once the sexual character of transmission was identified. The number of sexual partners a female prostitute has varies according to her occupational niche and the social class she serves. In general, she makes only limited discrimination among partners. The frequency of the use of barrier contraceptives was unknown though it was suspected not to be very common and that customers could eliminate the use of the condom by paying more. With the advent of AIDS and given the numbers of unknowns about transmission, the female prostitute (and by extension, the sexually very active woman) quickly became a group about which considerable concern was expressed.

Complicating this public health interest was the fact that prostitution in the United States is nearly everywhere against the law and in most places primarily managed by the criminal justice system. The conditions surrounding female prostitution are all socially marginalizing forces: the occupation is illegal and dangerous, it is associated with drug use, the workers are exploited (there are no OSHA rules), and most come from the ranks of the unskilled, the poor, and racial minorities.[29] No wonder the data needed for conclusive research were not available.

What was available came from the police and the health agencies, from reports on sexually transmitted disease and intermittent journalistic studies (some of quite high quality), from relatively rare ethnographic reports of social scientists and the autobiographies of prostitutes. The study of female prostitution languished in the social

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sciences following World War II. After the Kinsey reports provided evidence on the decline in the rates at which men went to prostitutes between the two World Wars, the systematic study of prostitution as part of either the sexual economy or the money economy became limited to a very small number of noncumulative studies. A revival of interest in prostitution came with the growth of feminist scholarship and the intense debate among feminists and between feminists and sex workers (as prostitutes came to label themselves) about the legitimacy of women's labor in the sex industry.[30] This is an issue that has yielded a new perspective on sex work (linking it in one direction to work of women in the industries connected with sex appeal—e.g., modeling, exotic dancing, acting—and in another direction to the similarity between sex for pay and sex for love and marriage in a patriarchal society). Unfortunately, this debate has yielded far more scholarly historical research and intellectual polemic than it has research about contemporary sex work.

Immediately after the onset of the epidemic there was a hue and cry about the dangers of transmission of HIV from women who gave sex for pay, and in a number of jurisdictions there were implementations of the police power to test for HIV seropositivity or to otherwise constrain sex for pay, constraints imposed entirely on women. The initiatives were taken with any evidence at all to support them and in some cases the AIDS epidemic appeared to be used as an opportunity to impose moral values under the guise of disease control.

At this time the Centers for Disease Control undertook a collaborative study of HIV seroprevalence among women who had sex for pay in a number of sites around the country. The research itself was somewhat rough and ready in its methodology (recruitment to the convenience samples differed from site to site, the quality of interviewing varied, and the interview instrument was disease driven). However, the data gathered on HIV seroprevalence was remarkably consistent. Most of the women in the study who were HIV positive were also intravenous drug users, and of the women who were not intravenous drug users, few were HIV positive. There is no evidence that there has been a sudden increase of HIV disease in the clients of prostitutes in this country, in contrast to what we know of prostitution in Africa.[31] While the Centers for Disease Control study focused primarily on women who worked in public locations (except for bordello workers in Las Vegas) and therefore does not represent

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women who work with a more affluent clientele in off-street locations, it is likely that the findings of the study can be generalized to these groups as well.

A number of factors might account for these findings, some of which are relevant to the disease process and some to prostitution. First, a good deal of the sexual contact between customers and prostitutes may be oral sex, which appears to be a far less efficient way to transmit the virus than vaginal or anal sex. Second, there is some evidence that many sex workers have their clients use condoms and that this practice may be increasing, at least in sites where there is an education program and women have control over their work conditions.[32] Third, it may be that heterosexual transmission depends on multiple exposure to those who are very ill with HIV disease or on the presence or the aftereffects of other sexually transmitted diseases.

On the other hand it is not impossible that the infection might be beginning in other groups of nonintravenous drug-using women who have sex for pay, particularly in individuals with histories of HIV cofactors such as sexually transmitted diseases. An upsurge in other such diseases among these women might contribute as a cofactor to HIV transmission, as it has in Africa.[33] Given the apparent limitation of HIV infection among prostitutes in the United States to those who are also intravenous drug users, the transmission of HIV out of these groups seems to result more from drug-related than from sex-related behavior.

The occupation of prostitution and its role in the sexual economy do not appear to be affected by the AIDS epidemic. If evidence shows that sexual transmission is fairly uncommon in this group, research interest in AIDS will decline in Western societies. Business will not be quite as usual, condom use may increase, sexually transmitted disease rates may fall, but sex work will remain the temporary occupation of unskilled working-class and minority women. Whatever changes are observed in erotic or occupational characteristics of prostitution will depend more on the efforts of sex workers and feminists to transform its legal and symbolic status than on the epidemic. The epidemic will affect only the lives of prostitutes who use intravenous drugs. Since the evidence that the disease spreads from these women to their clients is small, residual interest is likely to focus on the regular sexual

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partners of drug-using women, partners who are drawn from the same social milieu.[34]

THE ENDANGERED YOUNG

The best-documented area of sexual life since the Kinsey reports has been the changing sexual lives of adolescents and young adults, particularly those of young women. One of the critical findings of the Kinsey research and one of those that was most publicized was the finding that half the married women interviewed by the Kinsey team had had intercourse before marriage. Many commentators seized on this fact as evidence of the general moral collapse of the society. In the early 1950s there was an intense debate about the dangerous effects of petting on the young. What was most interesting about the Kinsey data was the degree to which this intercourse was truly premarital, that is, that the majority of the young women linked sex to getting married. Half of these young women engaged in intercourse only with the men they ultimately married, and only a small proportion reported having intercourse before marriage with more than five partners.[35]

What these findings signaled was that a new role for sex had developed as an integral part of the mate-selection process. Sexual activity between two young persons who were in love was evidence to each that the relationship was truly intimate. The willingness of a young woman to have sex with a man was a measure of emotional commitment, and the man in turn was expected to recognize the seriousness of this transition in the relationship. This pattern developed in the new middle class after the turn of the century and became a national norm after the Second World War. It was expected, though not entirely approved, that young people would pair off, fall in love, and have certain levels of sexual intimacy appropriate to their age group and closeness to marriage. There was always some variability in this process and some risk for those who were too sexually "advanced" at early ages. However, this was the expected pattern during most of the baby boom from 1946 to 1964, when early marriage was characteristic.

A large number of sociological studies recorded the existence of this pattern among the young and focused particularly on the correlates of what was then called premarital permissiveness.[36] For

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nearly two decades American sociologists investigated the conditions under which young people believed it was appropriate to have intercourse. They found that boys were in general more permissive than girls but that there was an increasing convergence between the genders toward a common standard of permissiveness with affection, that young people felt that love justified intercourse, particularly as they approached an appropriate age for marriage. The few studies that actually asked about the prevalence of premarital intercourse still found a substantial difference between the experience of young men and that of young women. Far more of the men reported engaging in premarital intercourse than did young women. From 1950 to 1970 the proportion of young women who had intercourse early in life increased slowly but significantly and the close link between intercourse and marriage eroded further. Having intercourse before marriage and after falling in love replaced the traditional expected sequence of pairing off, falling in love, marrying, and then having intercourse.

The social changes of the late 1960s along with the coming of age of the first wave of the baby boom, an increase in age of first marriage, and the sexual revolution as represented by the mass media accelerated the adoption of this new pattern. From 1965 to 1975 appears to have been the critical period. Studies conducted prior to 1969 suggest that there was a steady increase over the 1960s in the proportion of young women who had intercourse during their late teenage years. Studies undertaken in the first years of the 1970s and continuing into the 1980s reported a sharp increase in numbers of young women having intercourse before age twenty (indicating that the average age of first intercourse had sharply declined) and that the numbers of coital partners for these young women had increased.[37] The data were often not as detailed as might be desired, but they were consistent. By the early 1980s some 75 to 80 percent of young women had had intercourse before marriage, with some two to three sexual partners.[38] At the same time the evidence was that intercourse in early and midteen relationships was actually quite infrequent and that frequent and regular coitus appeared in the late teens and early adulthood. This increase in youthful sexual activity was widespread, though class and racial differences remained. Young women of middle-class origins started intercourse later than did those from less

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advantaged classes, and young white women started intercourse later and had fewer partners than young black women.

What makes this picture incomplete is the lack of data on young men. Sex research on young people during the 1970s was nearly entirely driven by the serious problem of adolescent pregnancy. In spite of the existence of effective contraception, the access of the young to contraception was neither universal nor easy, and the numbers of children born to unwed teenagers in all social groups grew rapidly during the decade.[39] A number of researchers found evidence of a steady convergence in the patterns of early heterosexual behavior among many young women and men, the young men accepting at least in part the necessity of an emotional relationship surrounding the sexual activity.

The data on the misadventures associated with this early sexual activity (unplanned pregnancies and births, sexually transmitted diseases, psychological trauma, sexual violence) indicated that young people in the 1980s were starting their sexual experience as ignorant of what it entailed as had their parents' generation. Starting earlier simply meant that more trouble could be expected. At the same time the increase in the age at first marriage meant that these early sexual experiences could not be automatically treated as truly premarital sex but now had to be addressed as part of growing up.[40] Few contemporary young people (except the most naive) expect that a sexual relationship beginning in the midteens is very likely to result in marriage.

Complicating this picture has been the steady increase in cohabitation as a pattern of pairing off prior to marriage. For some young persons premarital sex may have transmuted into precohabitation sex. Increasing numbers of studies suggest that cohabitation is quite common among young persons and that while some of these cohabitations result in marriage, many of them dissolve. Living together (perhaps more than one time) has become part of marital partner selection.[41]

This was the developing picture of young-adult sexuality when the AIDS epidemic was identified. Immediately there were fears that the epidemic would spread quickly among the young because of the evidence that while sex was common, caution was rare. Proposals were made to educate young people about the dangers of sex, especially those activities that were high in risk (e.g., anal sex), and to

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recommend the use of condoms to those who could not "just say no." This educational effort was immediately entangled in the preexisting debate about the appropriateness of sex education for the young, about who should teach the subject and what its content and goals should be. Despite studies to the contrary, many have believed that sex education increases rather than inhibits sexual activity among the young. It has been argued, correctly, that abstinence among the unmarried and sexual fidelity in marriage would be a perfect mechanism for reducing disease transmission. That the social changes required to produce these results would be extremely difficult to inculcate in the general population has not been understood, however. Because so many propose abstinence as a solution to contemporary sexual problems, it would be useful to identify the social changes necessary to inducing all members of the society to adopt the traditional sexual life-style.

Many national agencies are now engaged in school-based AIDS education, but if the past is any guide, the results in the classroom will be highly variable.[42] Educational programs must pass muster at many levels (the state, the school district, the school, parent groups), and each level will modify the program in various ways. Whether even the threat of HIV disease will change a situation in which nonjudgmental and complete information about sexuality can be given to young people in age-appropriate ways is unknown. Given the paucity of curriculum and trained teachers, future education seems like more of the same. Education for youth who are out of school can be explicit, but they are hard to reach. AIDS education for those of college age is likely to be sporadic simply because it is neither required as part of the college curriculum nor provided as a matter of course in the environment.

Efforts to provide accurate information about AIDS and HIV disease are in competition with both the mass media and the everyday sociosexual life of the young. The mass media now include many more references to sex than even two decades ago. Homosexuality as well as vaginal, oral, and anal sex and the role of safer sex in reducing disease transmission are regular topics. Television and theatrical films are remarkably explicit about sex, and TV soap operas are now based nearly entirely on nefarious sexual adventures. What would have been evidence for the fall of our American Rome in the 1950s is now accepted as part of our culture. The content of sex education as it

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relates to desire has become the responsibility of the mass media. The onset of the AIDS epidemic has simply intensified the preexisting public discussion of the sexual.

It seems very unlikely that the shape of adolescent and young-adult sexuality will be fundamentally changed by the AIDS epidemic as it is being currently played out. Only the most optimistic think that the impact of AIDS on the sexual behavior of the young will be very great, except in some degree to encourage the use of condoms. The inertia against changing social practices will blunt the effectiveness of directed education efforts as well as the impact of representations of AIDS in the mass media. Young people are far more influenced by each other and by the sexual practices current in their environment than they are by what adults tell them. To influence their conduct will require a major effort to confront young people about their current sexual behavior and recognizing that telling them to just say no is unlikely to have much effect.

The research programs under way among young people are largely aimed at assessing the current state of their conduct (whether they are having sex and how often) and evaluating the impact of educational programs. None of these studies will illuminate very clearly the processes of psychosexual development and the ways in which sexuality comes to play an important role in the lives of young people in U.S. society.

DRUGS AND SEX

"AIDS, Sex and Drugs: Don't Pass It On" is an advertisement posted in both English and Spanish on the New York subways. Illustrating this message is a picture of a man and woman joined face to face into one body inside a syringe. Out of the needle comes a stream of blood that ends in a blob, inside of which there is a fetus. While not explicitly showing the most common sequence of transmission, which begins with the sharing of needles during intravenous drug use, continues in sexual transmission to a partner, and eventually results in transmission to the infant, the advertisement presents the problem dramatically. Immediately after the realization that the HIV virus (not known to be the cause of AIDS at that time) was appearing in intravenous drug users, primarily members of racial and ethnic minorities, epidemiological studies quickly identified needle sharing

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as the source of transmission. Secondary sexual transmission appeared to be very likely, and serious concern was expressed about transmission to non-drug-using sexual partners and then from those partners into populations at lower risk. It remains difficult in many cases to disentangle whether transmission is a result of sharing needles or sexual activity since many of the sexual partners of intravenous drug users also use drugs and may share needles. There is, however, firm evidence of independent, though variably efficient, vaginal transmission of the virus.

The intravenous drug user is perhaps the most marginal figure in the AIDS epidemic. Most intravenous drug users are black or Hispanic. Many of them live in poverty on the edges of urban life. They fill the prisons and jails and are usually described as weak-willed, pleasure-seeking hedonists, unable to control themselves, willing to do anything for a fix, unreliable when offered treatment. In the fifteen years before the opening phase of the epidemic, New York had estimated that it had 200,000 intravenous drug users, but drug-treatment programs had ossified and no new treatment slots were being created. Waiting lists were long and programs unevaluated. The drug-use problem was securely in the hands of the criminal justice system. Public concern about drugs rose and fell with media campaigns, and those mugged or burglarized complained but with little consequence. Drug use was one of the accepted miseries of urban life.

When the epidemic began, interest in the intravenous drug user suddenly surged and focused on the danger of needle sharing and on the availability of treatment.[43] As the AIDS–drug agenda has evolved, concern has grown about the sexual conduct of drug users. Studies have been initiated, but little data have been published. At this moment, interest in behaviors that promote transmission and in educating persons to use safer sex procedures shapes nearly all data-gathering efforts.

In the past, continuous heroin or other opiate use was believed to inhibit sexual activity, particularly for men. This belief was based on only a small amount of unsystematic data. There was some evidence that women who were intravenous drug users worked as prostitutes to support their addiction (and perhaps that of their steady partners). With the advent of crack have come anecdotal reports of young women exchanging sex for drugs. In extreme cases, young women

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stay in crack houses and have sex with a large number of men in order to keep up a supply of drugs. Until systematic research on these practices is conducted, it is reasonable to be cautious in drawing conclusions about the extent of their use and the aphrodisiac potential of crack and cocaine.

The recognition that intravenous drug users have steady affectional and sexual partners as well as families may well be one of the most important discoveries resulting from attempts to intervene in sex-related transmissions. Like most persons who live on the social margin, intravenous drug users usually have conventional social relationships in which they spend a good part of their lives. These relationships are attenuated by the exigencies of drug use (and now by HIV disease among those who are infected), but they often rebound during periods of nonuse.

Class, ethnic, race, and religious influences will no doubt alter the sexual practices of intravenous drug users as well as those of the rest of society. Drug users may turn out not to be such strangers to the rest of the society if we examine the ways in which their behavior overlaps that of the nonintravenous-drug-using majority. In the absence of large-scale policy changes, however, many drug users will be infected with HIV. Most will die. To wish for AIDS to solve the problem of intravenous drug use is to ignore the steady recruitment of new users (and perhaps new needle sharers) over the course of the epidemic.

THE HETEROSEXUAL "COMMUNITY"

Many of the efforts at disease control have been directed at preventing HIV transmission into the heterosexual segment of the population, often mislabeled the heterosexual community. This misnomer conceals the fact that heterosexuals are not organized into a community based on their sexuality. Heterosexuality is taken for granted. Most men who desire women and most women who desire men do not think of themselves as heterosexuals. The troubles they have with sex are sexual troubles, not heterosexual troubles, though it might be helpful if they began to think of such troubles as having their basis in their heterosexuality.

Persons can be heterosexual in many ways. Just as studies of gay men and lesbians have come to be studies of homosexualities, so the

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study of heterosexuality needs to be reinterpreted as the study of a wide variety of sexual life-styles. There is a tendency to see heterosexuality as having a life of its own, expressed in adolescence, in marriage, during divorce, and in old age. It may be fruitful to see heterosexuality as a dependent variable serving different social and psychological needs when it is expressed, for example among young people, those in couple relationships, those having sexual activity concurrent with a primary relationship, or those using sex for pay. These relationships have different scripts. While the sexual object is constant, little else of importance may be.

Heterosexuality varies across social strata and social networks. Sexual practice between men and women is influenced by class, race, ethnicity, and religion as well as by marriage, children, divorce, health, and occupation. The Kinsey studies probably demonstrated only one finding about which there could be no doubt: that the variation of sexual expression in the United States was nearly entirely controlled by social factors (gender, class, religion, education, and marital status). Thinking about heterosexuality in these ways creates a far more formidable task for research than does a more traditional perspective, which sees heterosexuality as an undifferentiated essence waiting to be expressed.

The Kinsey group had asked a wide variety of questions about sexuality and set a standard for coverage of sexual items that has not been matched since. While coverage was extensive, however, it was often not intensive. Kinsey reported that a large proportion of those divorced had intercourse in the post- or intermarital periods, but beyond incidence, frequency, and number of partners, there was little reported on the relation of that sexual activity to the process of divorcing and reconstituting new relationships. The Kinsey reports made similar limited findings about extramarital and marital sex but did not relate them to other factors.

In the period between the Kinsey studies and the early 1980s a wide variety of studies was undertaken to examine the role and importance of sex during marriage, in marital dissolution, and in recoupling and having second families. These studies show that sequential patterns of cohabitation, marriage, divorce, and remarriage are now normative in our society. Sexual activity moves from the relatively constant, when persons are in relationships, to the relatively inconstant, when those relationships break up. Between

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couple relationships there is an increase in sexual partnering as persons eagerly seek new relationships. A number of important social forces underpin this pattern, forces very unlikely to be countered by the current pressure of the AIDS epidemic.

As excellent as some of the research studies are that outline this trend, it would be hard to argue that there existed a systematic and reliable body of sample-based quantitative data on any of these processes at the time the epidemic was recognized. The epidemic has now posed its own questions about the structure of sexual relations among the heterosexual majority. These questions are quite different from those posed by researchers in the prior three decades. Earlier researchers on extramarital sex were concerned about how such conduct affected the stability of marriage, the logistics of affairs, and the psychological impact of infidelity. They also attempted to estimate the prevalence of extramarital sex, numbers of partners, and frequency of sex in relationships, but such studies were rare and based on adventitious collections of respondents.[44] It was exactly these questions of prevalence, number, and frequency on which the epidemiologists focused, for this was the information that would be predictive of whether the virus would spread in these populations. How many partners people had and how often they had sex together over some period of time was the kind of data needed for predicting the course of the AIDS epidemic in the general population.

The data the epidemiological modelers need concern the structure of sexual networks in the society.[45] Who has sex with whom is a question of social structure, since persons do not mate randomly. Depending on how precise the data needed for the differing models may be, it becomes important to know numbers of sexual partners, frequency of sexual activity, and sexual techniques in each type of contact as well as the social attributes of sexual partners. How much interracial sexual contact is there, and how constrained by social class and religion is it? Is sexual contact in or out of stable and monogamous relationships, and does it involve more or less risky sexual techniques? Are the patterns different for male-male sexual relationships in contrast to female-male contacts? Are there differences between relationships for pay and relationships with one-time or casual partners?

Such questions direct research interest away from the image of the sexual individual to the sexual transaction between two or more

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individuals.[46] Even more than the Kinsey approach, such research emphasizes the social dimensions of sexual conduct and the ways in which microsocial networks organize and offer opportunities for sexual activity. The interest in AIDS has stimulated an alternative image of the ways in which sexual life is organized. Networks of needle exchange, networks of social support for those who are ill, networks of influence in scientific research groups have become the subjects of the major studies of sexual conduct. The needs of the epidemic have thus produced a new approach to the study of sexuality.

Studies of the general population are now being undertaken, as are specialized studies of minorities. Such studies will not begin to yield data until the early part of 1990 or later. There is evidence from some surveys that household sample surveys are yielding lower prevalences of sexual conduct than have other surveys based on convenience samples.[47] If these preliminary data are correct, it may well be that the U.S. society displays less sexual behavior than previously thought and that the collective representations of sexuality in the mass media are far more erotic than the lives of those who see these representations.

At this moment we have not learned a great deal about the sexual life of the general population from AIDS-generated research. We are just at the forefront of such studies.

* * *

If the epidemic maintains its present course, in the United States it is most likely to become primarily a disease of the poor and minorities. The virus will be transmitted more commonly in populations that are already burdened by many health and social problems, and there may be some relatively infrequent infections of other segments of the population through sexual activity and shared needles. The impact on the sexual life of the society will largely be restricted to reshaping the lives of gay men so that they will tend to live as couples in a less erotic way of life. Anal sex has already become less common and less a marker of the boundary of gay identity. The research programs that have been conducted in the gay community have largely been devoted to disease issues and are less often relevant to gay identity and gay community life. The record of the impact of

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AIDS on gay life is far more likely to be found in small-scale studies, in the intellectual gay press, and in novels and autobiographies.

It is unclear how the epidemic will affect the sexual conduct of either bisexuals or women in the sex industry. AIDS-driven studies of these population groups in the sex industry have usually not directly addressed issues of desire and occupation. In some studies of minority men who have sex with both men and women, the concern has been to find cultural determinants of sexual conduct. In a few studies of female prostitutes there has been an effort to understand their lives as part of an occupational milieu managed largely by men. In some of these studies research and education have been based on understanding that these women often have children, lovers, leisure time, parents, and nonprostitute work histories. Not much further research on prostitutes is to be expected, though additional research is likely to be conducted on bisexuals because of a potential danger to the blood supply.

HIV is primarily a threat to the young via intravenous drug use and sexual relations with users who are infected. It is not clear whether middle-class or otherwise conventional young people are in grave danger of infection. Education to reduce risky behavior is unlikely to eliminate much sexual activity, though the use of condoms may make a comeback in youthful populations.[48] If so, it will have the beneficial consequences of reducing pregnancy and the transmission of other sexually transmitted diseases. It is extremely unlikely that there will be major reductions of numbers of sexual relationships among the young even by the most determined AIDS education programs. Young people may get more accurate information about sex as a result of AIDS these days, and their sexual lives may be better chronicled and perhaps understood than before, but making behavior change effective is only a hope.

The greatest promise for AIDS education lies in working with targeted groups in clinical settings where health services to those most at risk are delivered—drug-treatment centers, family-planning centers, health-maintenance organizations, sexually transmitted disease clinics, emergency rooms. Even there, only limited goals can be attempted—people may use condoms but are unlikely to stop having a number of sexual partners. The cycle of coupling, uncoupling, and recoupling is now accepted as the dominant sexual pattern in the United States. Changing it will take more social science understand-

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ing and political will than is likely to be mobilized. As long as the representations and the reality of the epidemic remain as they are, the trajectory of sexual change will remain much the same.

Doing good research may or may not lead to a more reasoned vision of sexuality in the lives of individuals and our culture, but we may be sure that without the knowledge this research would give us, that vision will be impossible.

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Ronald Bayer

AIDS, Privacy, and Responsibility

In AIDS, the most intimate dimensions of human existence, often the sources of our deepest pleasure, have been welded to the threat of lethal disease. As an epidemic with roots in private acts, AIDS forces into the social realm matters that liberal societies have increasingly sought to protect from public scrutiny and legal control. That in the United States AIDS is a disease of those who have sought the protective mantle of privacy—drug users because of the illicit nature of their behaviors, gay and bisexual men because of the historical burdens of stigma and criminalization—has indelibly marked the epidemic.

Each of these factors has contributed to the extraordinary political context in which public health officials have been compelled to confront the task of altering the epidemic's course and has informed the often bitter controversies over how the interests of public health and of privacy might be balanced and reconciled. In the clashes that have punctuated the first eight years of the American AIDS epidemic, the influence of both individualism—reflected in the ideologies of those who have sought to protect the privacy of persons most at risk for HIV infection—and of the communal perspective—reflected in concern for public health—have been brought to bear.

A public health strategy to limit the spread of HIV infection will be effective only if it produces dramatic, perhaps unprecedented,

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changes in the sexual, procreative, and drug-using behavior of millions of adults and adolescents. Our collective fate is utterly dependent on private choices, choices that will be made in the most intimate of settings beyond the observation of even the most thoroughgoing surveillance.

We are ultimately dependent on the emergence of a culture of restraint and responsibility to shape such choices. At a minimum, such a culture must underscore the importance of preventing harm to others through HIV transmission and of preventing the birth of infants with AIDS. In a more robust form, it would go further, stressing communal concern about the extent to which individuals place themselves at risk for infection with the AIDS virus.

Like all grave social challenges, stemming the AIDS epidemic requires that individuals transcend their self-interest and gain a sense of communal responsibility, that they recognize the moral obligation to desist from acts that may place others at risk. That it is the most private dimensions of daily life that are implicated in the transmission of HIV infection will make this transformation very difficult to accomplish. Vigilance and self-protection will, of necessity, remain critical. But the protection of others, of intimates, is the moral standard against which behaviors will have to be judged.

The problems the new epidemic poses resemble the problems posed by other behavior-related diseases—lung cancer, emphysema, cirrhosis—with which public health officials have had to deal since the surgeon general issued his first report on smoking in 1964. At the very moment that an ethos of privacy was being enunciated, drawing on the strong cultural tradition of American individualism, the collective significance of every individual's acts began to assume greater salience in public debates.

The publication in 1975 of *A New Perspective on the Health of Canadians* represented a renewal of the public and official discussion of the role of government in modifying personal behaviors linked to disease and death. In that report, Marc Lalonde, Canada's minister of national health and welfare, bluntly noted that unless dramatic efforts were made to reduce environmental and self-imposed risks, little could be done to affect the pattern of morbidity and mortality. Lalonde was alert to the nature of the opposition his challenge could provoke: "The ultimate philosophical issue . . . is whether and to

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what extent government can get into the business of modifying human behavior, even it it does so to improve health."[1]

These themes found expression in the United States two years later with the publication of the widely read and debated essay "The Responsibility of the Individual," by John Knowles, president of the Rockefeller Foundation. The communal consequences of self-destructive individual behavior could no longer be tolerated, he asserted. The social costs were simply too great. Only if individuals assumed greater responsibility for their own health could the staggering burden of health-care costs be brought under control: "The choice is individual responsibility or social failure. Responsibility and duty must gain some degree of parity with right and freedom."[2]

The untoward social, but especially economic, consequences of individual behavior were to become the leitmotiv of the American debate over health, life-style, and government policy. In his introduction to *Healthy People*, the American analogue to the Lalonde report, Joseph Califano (then secretary of health, education, and welfare) wrote, "Indulgence in private excess has results that are far from private. Public expenditures for health care are only one of the results." While acknowledging that there might well be controversy and debate about the appropriate role of government in urging citizens to give up their pleasurable but harmful habits, Califano argued that "there could be no denying the public consequences of these private acts."[3]

For some, the tone of the literature on individual behavior and health in the 1970s was unacceptably moralistic. Critics on the left were especially acute in focusing on the ideological function of a literature that they believed sought to mask the social roots of behaviors that were so clearly linked to illness and death.[4] Opposed to those perspectives that sought to burden individuals with the demand for behavioral change, and doubtful that individuals could within the context of the social matrix that limited their options effectively make such changes, critics stressed the need to transform the institutional sources of the threats to the collective well-being. "The focus of postmodern public health," wrote a communitarian critic of the literature on life-style and disease, "is on controlling hazards rather than changing behavior, on prevention through control of market activities and other social structures which expose people to hazards and collective responsibility as opposed to self

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interest."[5] AIDS would pose a challenge to the adequacy of such formulations that relegated changing behavior to the premodern conception of public health.

Haunting the debates was a profound concern about matters of privacy, liberty, and the legitimate boundaries of public authority. Aaron Wildavsky forcefully articulated the fears that found expression in popular as well as in elite opinion when he wrote, "We are not talking about peripheral or infrequent aspects of human behavior. We are talking about some of the most deeply rooted and often experienced aspects of human life—what one eats, how often and how much; . . . whether one smokes or drinks and how much; even the whole question of human personality. . . . To oversee these decisions would require a larger bureaucracy than anyone has yet conceived and methods of surveillance bigger than Big Brother."[6]

If the discussion of how health officials might act to modify cigarette and alcohol consumption as well as vehicular behavior could provoke such consternation, how much more intense would be the concern when the transmission of HIV infection was involved. In each of the former cases government could, if it chose to, radically affect the social context of private behaviors through product design, through pricing and taxation mechanisms, through the regulation and control of acts that take place in public. Invasions of privacy would be largely unnecessary. With the transmission of HIV, the public dimension of the acts that are critical to public health is exceedingly limited. The bedroom, not the highway or the commercial outlet for alcohol or tobacco, is involved. More important, sexual behavior and childbearing decisions are not the equivalents of smoking, drinking, and driving. They touch on intimate decisions that only the most totalitarian society could, without great trepidation, consider the realm of appropriate direct state regulation.

In the face of the AIDS epidemic the central problem before public health officials is how to change AIDS-related behaviors and the social norms that guide such behaviors. The very privacy of the acts involved in the transmission of HIV infection imposes practical limitations; the importance of eliciting the cooperation of those most at risk for AIDS and of fostering the development of a culture of restraint and responsibility imposes political limitations; and the importance of privacy and civil liberties to American society imposes ideological limitations on the public health strategies that can be

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called on in the struggle against the epidemic. Both philosophical and pragmatic considerations thus dictate a broad common program within which the defense of public health and respect for privacy are joined.

Yet the struggles over the appropriate course of public health policy during the first eight years of the AIDS epidemic reveal how much of an oversimplification it is to suggest that the claims of public health and privacy must invariably coincide. Indeed, a more accurate characterization of the events that have defined the first years of the epidemic would underscore how very different understandings of the demands of privacy and of the imperatives of public health informed the political controversies that centered on how best to proceed to limit the spread of HIV infection. How much these conflicting perspectives could affect the judgment of those locked in battle was starkly revealed in the encounter over how or whether to regulate the public contexts within which many urban gay men engaged in sexual activity linked to the epidemic's spread.

PRIVATE ACTS IN PUBLIC PLACES

Very early in the epidemic, the limitation of the perspective focusing solely on the decisions about sexual conduct made by gay men as private individuals became apparent. This was the context in which the question of the bathhouses, those bold expressions of an unfettered gay sexuality, became the subject of an acrimonious controversy that divided the gay community and forced a confrontation over privacy, sexual behavior, and limits of state intervention in the name of public health. "Could [it] be," wrote the publisher of the *Advocate*, a West Coast gay newspaper, "that the sex palaces which encourage orgies and lack adequate showers are public health hazards? . . . I shudder at the political implications of this notion."[7] Randy Shilts, the gay *San Francisco Chronicle* reporter and author of *And the Band Played On*, who was to emerge as a strong antagonist of the bathhouses, the sexual culture they fostered, and the timidity of gay political leaders in confronting the public health implications of the continued operation of such establishments, was even more blunt in his denunciations.[8]

Despite occasional suggestions that the gay community might have to collaborate with public health officials to regulate the bathhouses

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or to limit the activity permitted to occur within them, the dominant ideological voice projected by the gay press was antistatist. It was hostile to the claims that the defense of public health by government officials might rightfully entail restrictions on commercial establishments serving the sexual desires of their gay clientele, hostile to the suggestion that the gay community act to force changes in the institutions providing the setting for anonymous sexual encounters that could lead to the spread of AIDS.

Having so recently emerged from long, bitter struggles against statutory prohibitions on homosexuality and the socially sanctioned pattern of discrimination that made privacy so central to the struggle for survival, it is not surprising that gay political thought was so libertarian in its orientation. Indeed, despite the language of community that filled the columns of the gay press, a radical, almost asocial individualism inspired much of the early rhetoric about the bathhouses.

One of the most forceful and principled defenses of the importance of shielding the right of adults to conduct their sexual lives free of state interference, even in the face of decisions that could lead to illness and death, came from Neil Schram, president of the American Association of Physicians for Human Rights, a gay-health professional organization.[9] Provoked by the announcement of San Francisco's director of public health that he was prepared to close the baths and drawing on the antistatist and individualistic themes of gay political thought and the ever-present concern that sodomy laws might be reenacted, Schram linked the debate over the bathhouses to those that had raged over other behaviorally related diseases—those caused by smoking, alcohol consumption, and overeating, and to the risks associated with motorcycle riding without helmets.

Since personal freedom was at stake, only a posture of laissez-faire was tolerable, Schram said. Physicians had an obligation to educate and warn about high-risk behavior, but it was not for the medical community or the state in its public health role to enforce behavioral norms. "The closing of businesses to protect people from themselves cannot be accepted. . . . Ultimately each individual is responsible for himself," stated Schram. To permit the closure of the bathhouses would be to permit an assault on an institution "where it is safe to meet other gay people without fear of arrest and harassment" and

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would represent the "beginning of the end." An ineluctable course led from the public bathhouse to the private bedroom.

The memories of oppression were all too fresh. Repeating the leitmotiv of virtually every pronouncement in the organized gay medical community, Schram concluded that though he and his association sought to discourage sexual behavior that might increase the risk of AIDS, "we cannot and will not support any effort to enforce that viewpoint."

Some gay medical professionals, however, viewed the baths as threats to the health of gay men and supported severe restrictions, even closure of the baths. Haunted by visions of their dying patients and by the toll AIDS was taking, these professionals saw the bathhouse as a unique environment in which the disease could spread. Some were moved by the knowledge that their own patients, acting as agents of further infection, continued to attend the baths. Hopes that the threat of transmitting a lethal disease would result in a radical modification of behavior had met with bitter disappointment. There was no alternative; the claims of privacy and civil liberties had to be subordinated to the demands of the public's health.

Eventually, health officials in New York State and in San Francisco did move to close the baths, but only after protracted struggles. That they as well as others had not moved more forcefully in the first years of the AIDS epidemic was in part a consequence of the political constraints imposed by having to chart a course compatible with a policy of cooperation with gay men, who viewed all agencies of the state with profound suspicion. Public health officials were also restrained by the impact of liberal political values since the centers of the AIDS epidemic were cosmopolitan cities with political cultures of relative tolerance in which sexual privacy was a preeminent concern. Finally, officials recognized that bathhouse behavior was but a very small part of the vaster problem of a pattern of sexual behavior that occurred in settings beyond the reach of the state. Prudence dictated restraint.

Too often, however, the result was timidity and a failure to appreciate the ways in which a public culture of sexual restraint and responsibility could be fostered by the interventions of health officials. If regulating or closing the baths could not directly affect the course of the epidemic—the number of gay men who still attended them was relatively small—the symbolic significance of such public

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health measures could nevertheless have served as a powerful statement about the dangers of promiscuity, about the importance of self-protection and the protection of others. In an epidemic where educating millions about the necessity of radical changes in private behavior was widely acknowledged as fundamental, the failure to appreciate the importance of symbolic measures was a profound misjudgment, a misjudgment conditioned by the political forces evoked by the AIDS epidemic.

TESTING AND SCREENING

If the bathhouse controversy had centered on the role of the state in regulating intimate acts engaged in in public places, the issue of HIV antibody testing raised worries about the extent to which the state would try to make public the individual's secret of infection. How would those at risk be encouraged or compelled to come forward so that they might confront the danger they posed to others? How would they be counseled? How would evidence of infection be used to establish and then perhaps enforce norms of behavior? How would the evidence of infection be used in establishing restrictions on the opportunity to work, go to school, obtain insurance, remain free?

Months before the AIDS virus antibody test was licensed by the Food and Drug Administration for use in blood banks, anxiety had already surfaced in the discussions of gay leaders. "Don't take the test" became the rallying cry.[10] Even before the test was available, elements of what would harden into an orthodoxy had been articulated by gay leaders: the test was technically limited; the findings it produced would be of no benefit to the individuals tested or to their sexual partners; those who were antagonistic to gay interests would seize upon the test to foster irrational discrimination in the guise of public health. Behavioral change was critical for survival, yet testing might lead only to identification and stigma.

As greater understanding of the test's scientific and public health significance emerged in late 1985, those who were antibody positive were infected and could be presumed to be infectious—public health officials, especially at the Centers for Disease Control, began to press for wide-scale voluntary, confidential testing and counseling of those who were at increased risk.[11] To encourage such voluntary testing, public health officials, under pressure from gay leaders and their

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political allies, began to assert that carefully crafted protections for confidentiality must be guaranteed and that stringent antidiscrimination legislation was necessary. Public health was thus dependent on, and not antagonistic to, the protection of the privacy and the social interests of the infected. In many states officials attentive to the fears of gay men and concerned about the possibility that at-risk individuals might seek free testing at blood banks, sought to encourage such testing by making the option of anonymity available in special settings.

But gay political, medical, and social organizations remained adamant in their opposition to the notion that wide-scale testing had any role to play in fostering behavior change, even when it was acknowledged that for a very few individuals that might be the case.[12] Fear of how mass voluntary testing and counseling could produce a disastrous train of events for those identified as infected, rooted in the social experience of American homosexuals, had thus driven the mainstream of gay political and medical organizations into a defensive posture. Dismissive of those who claimed that testing could serve a vital role in fostering behavioral change and suspicious of the intentions of those who would devote considerable resources to a counseling program linked to testing, gay leaders responded with a rigidity for which only time and the ever-growing impact of the epidemic would serve as an antidote. Anxiety about threats to privacy had thus compelled a stance that would challenge at every turn efforts to use the HIV antibody test and counseling as a tool for mass behavioral change. Despite such resistance, public health officials at local, state, and federal levels persisted in pressing for an expansion of voluntary testing as a way of identifying those who had no reason to believe that they had been infected and as a technique for underscoring the importance of changed behavior in those whose lives had placed them at risk.

Such a commitment did not, however, represent a deviation from the broad consensus forged by public health officials, in large measure out of intense and often acrimonious confrontation with gay leaders and advocates of civil liberties. Voluntarist at its core, it was a consensus marked by an appreciation of the gravity of the AIDS epidemic and a recognition of the very limited role that coercive public health measures could play in the years ahead. Perhaps most critically, at the base of this consensus lay the recognition that some coercive

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measures could harm public health by driving those most at risk of infection into defensive postures, by subverting the prospects for the broad-scale modification of private behavior. Both the surgeon general of the United States[13] and a special committee established by the Institute of Medicine of the National Academy of Sciences[14] underscored these themes in reports issued in the fall of 1986.

Some found the voluntarist consensus too timid, too much of an accommodation to those who sought to restrain the effective use of the government's authority to protect the public's health. It was not the limits imposed by AIDS, its modes of transmission, or the absence of effective medical prophylaxis but the triumph of interests committed to the protection of privacy that accounted for the peculiar disjunction between the gravity of the situation confronting America and the prescriptions that had been put forth. At first the sectarian right wing of American politics gave this challenge articulation. Eventually it found a sympathetic hearing among conservative politicians and the White House under Ronald Reagan. Those opposed to the voluntarist consensus centered their argument on the belief that mandatory screening could be used to identify the infected so that "appropriate" restrictions could be imposed on them.

In a few settings mandatory testing for the antibody to the AIDS virus had been adopted without protest because of the virtually universal recognition that an important public health good, not otherwise attainable, would be secured. Screening of blood, organ, and semen donors provoked little outcry—after the initial uncertainties of 1985 in blood banking—because all parties understood that the exclusion of contaminated body fluids and tissue from the donor pool was essential for the protection of others. In virtually all other settings proposals for mandatory screening have provoked controversy, not only because of the invasion of privacy and the coercion involved but also because of the restrictive and exclusionary purposes they have been designed to serve.

Recruits to the armed forces were to be screened to deny access to military service,[15] those in the foreign service to preclude assignment abroad,[16] Job Corps applicants to prevent placement in residential settings,[17] prison inmates so that they might be segregated,[18] employees in the private sector so that they might be denied work,[19] applicants for health and life insurance so that they could be deprived of coverage,[20] hospital patients so that they might be treated with

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special caution[21] (perhaps not treated at all), those seeking to immigrate so that they could be barred from America.[22] The politics of mandatory screening has, in short, been almost uniformly the politics of exclusion but to no demonstrable public health end, for AIDS is spread behaviorally.

DANGEROUS ACTS

Haunting the discussion of mandatory screening has been the dread that ultimately, quarantine, the most restrictive and coercive element in the panoply of public health weapons, would be used in the struggle against AIDS. Hadn't that extraordinary power been used in prior eras when society confronted epidemic disease? Hadn't the power to isolate been brought to bear when socially unpopular minorities had been viewed as the source of social contamination?[23]

Though there have been some calls for the mass quarantine of all HIV-infected individuals, usually from those at the right wing of the political continuum, they have been remarkably rare. On grounds of science, pragmatics, and liberal constitutional values, proposals for the mass isolation of all infected individuals have found no support among those professionally concerned with the practice of public health, and little among politicians.

Proposals for mass quarantine clearly posed a profound threat to the most fundamental commitments of those concerned about the constitutional limits of state power. Since HIV transmission occurs because of specific behaviors on the part of the infected, mass quarantine would necessitate a willingness to confine individuals on the basis of predictions about their future dangerousness. It would be the equivalent of mass preventive detention on an unprecedented scale and would, as Larry Gostin, executive director of the American Society of Law and Medicine, has written, "carry in [its] sweep persons who are determined to forgo the high-risk behavior that makes transmission possible; persons who are no longer infectious because the virus had eliminated its host cells; and persons who are so debilitated or demoralized as to be unable to engage in high-risk behavior." Since HIV infection is lifelong, there is no logical point at which those detained could be released—the result would be "a kind of civil life commitment."[24]

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If the confinement of all HIV-infected individuals has been dismissed as irrational and unworthy of any serious consideration, that has not been the case with the question of how to respond to those who, though infected, continue to behave in a way that places unsuspecting sexual partners at risk. This issue became a source of bitter and divisive conflict as some state health officials sought to invoke their historic powers to control the sources of communal infection. Even when efforts were made to develop carefully circumscribed interventions in ways that conformed to contemporary constitutional notions of the requirements of due process, the opposition was profound.

Gay leaders have repeatedly argued that quarantining AIDS patients, even the few irresponsible patients, would have no impact on halting the spread of AIDS. Only by teaching the sexually active, both heterosexual and homosexual, how to protect themselves can the spread of HIV be controlled. Understanding how HIV is transmitted, gay leaders have asserted, is the ultimate source of defense for both individuals and society. Assuming personal responsibility for self-protection is a more reasonable response to the risk of AIDS than threatening quarantine, "than seeking to scapegoat those already ill."[25] In the context of the most intimate of relations, vigilance rather than trust is to be the norm. For the "exceptional case" of the irresponsible AIDS patient, it is necessary to provide appropriate social supports—counseling and guidance, not the threat of incarceration.

Like gay groups, civil liberties organizations opposed the use of state power to control individuals whose sexual activity placed others at risk. When the American Civil Liberties Union considered this matter, it forcefully objected to all efforts that might entail the application of either public health law—with its forward-looking features—or criminal law—backward-looking in principle—to meet the challenge of the transmission of a lethal disease in intimate settings. According to the ACLU, the dictates of sexual privacy were such that even the willful exposure of an unsuspecting but "consenting" sexual partner did not provide grounds for government intrusion.

Like the bathhouse controversy, the struggle over quarantine, whenever it arose, took on important symbolic dimensions. To the advocates of even the most limited application of the power of

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quarantine, it was important to articulate the presence of public health values, though people of this opinion knew that as a practical matter efforts to control the infected and irresponsible who were easily identifiable would have only marginal significance for the epidemic. To the defenders of civil liberties and to gay leaders, it was critical to protect the realm of privacy and sexual behavior from state authority, even when such authority was exercised in response to egregious circumstances.

TEACHING PREVENTION

At every threat of coercive public health measures such as mandatory screening and quarantine, gay leaders, civil libertarians, and a broad alliance of physicians and public health officials committed to a voluntarist health strategy for combating AIDS have demanded that education provide the central, if not the sole, element in the preventive response. More money, more inventiveness, more boldness were necessary if individuals were to be taught how to protect themselves from HIV infection, if they were to learn how to protect their sexual partners or those with whom they shared intravenous drug equipment, if they were to prevent the birth of babies with AIDS.

Here was a public health strategy that was utterly compatible with the protection of the private realm, a strategy for the modification of private acts with dire social consequences that did not employ the coercive power of the state. It was a strategy dictated by political and moral commitments as well as by the unique epidemiological features of an epidemic that spread in the context of intimate relationships. In the face of a dire public health challenge, it appeared that public health officials had little political, practical, or moral alternative but to turn to the weakest and least-understood instrument of social intervention.

Despite the very early and broad appreciation of the role that risk-reduction education might play in the control of AIDS, the federal government did virtually nothing to fund such efforts in the first years of the epidemic. *Confronting AIDS*, a report issued in the fall of 1986 by the National Academy of Sciences and the Institute of Medicine, underscored the nature of the government's failure: "Because no vaccine is likely to become available in the near future and because of the seriousness of the disease, the only prudent course of

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action is an immediate major effort to stop the further spread of infection through public health measures, particularly education. Any delay will bequeath to future policy makers a problem of potentially catastrophic proportions and will condemn many thousands of individuals to infection and death." Faced with the enormity of the epidemic's potential toll, past and current efforts could only be described as "woefully inadequate."[26] The failure of government not only had disturbing implications for the public's health, for the health of gay men, intravenous drug users, and their sexual partners, but represented a great moral lapse in the face of the epidemic's challenge.

The inadequacy of federal funding for education efforts designed to limit the spread of AIDS had roots, however, that went deeper than the fiscal constraints that hobbled national efforts to control the epidemic. The very prospect of a major government effort to underwrite risk-reduction education was mired in controversy from the outset. How could it have been otherwise? How could government agencies teach gay men about "safer" sexual practices when homosexual acts were criminal offenses in half the states? How could such agencies teach addicts about the sterilization of drug paraphernalia when the use of heroin and cocaine constituted criminal offenses in every state?

The reluctance to fund safer-sex educational material went beyond revulsion provoked by the proposed use of "street language" and sexually explicit drawings and photographs. To those who believe that AIDS is the consequence of the erosion of traditional values, of a sexuality unrestrained by heterosexual monogamy, the very premises of the AIDS education efforts being encouraged by public health officials under pressure from gay leaders were profoundly flawed. In the reactions to the surgeon general's *Report on Acquired Immune Deficiency Syndrome*, published in October 1986, the intensity of such ideological opposition was revealed and the political power of the opposition demonstrated.

To those who had feared that the surgeon general would use the opportunity of his statement on AIDS to the American people to advance the conservative social perspective of the political constituency to which he had been popularly linked, the report came as a welcome surprise. To those who had anticipated that their ally in the social movement against abortion would seize the opportunity to

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stress the importance of traditional sexual morality, the report represented a betrayal.[27] In Secretary of Education William J. Bennett, those who felt betrayed found their voice.[28]

Like the attempt to modify sexual behavior among gay men, the effort to address intravenous drug users about the risks they pose to themselves and their sexual partners evoked controversy from the outset. If safer-sex literature provoked conflict because of explicit language and the tacit toleration of homosexuality, messages to addicts about the importance of avoiding contaminated drug paraphernalia and instructions on how to sterilize used equipment suggested an unacceptable retreat in the seven-decade medical-legal effort to suppress drug use.

Opposition to this effort came not only from those who found it politically offensive. The very prospect of informing drug users about how they could continue using drugs without risking HIV infection was a source of discomfort to those with a professional commitment to preventing drug use and to treating those addicted to illicit substances.[29] Inhibited by such reactions, inadequate resources, and the absence of community groups that could reach out to drug users in the way gay organizations had served gay and bisexual men, preventive efforts among intravenous drug users remained negligible.

Nevertheless, evidence did begin to surface as early as 1984 that knowledge about the risks associated with the use of unsterile needles had begun to penetrate the subcultures of drug abusers. Researchers in New York City found that used needles were being repackaged and sold as new. They concluded that "the demand for new needles has reached a point where it can now support a supply of counterfeit new needles."[30]

These findings revealed that drug users could be reached with messages about the threat of AIDS but also suggested that prohibitionist policies restricting the sale of sterile syringes and hypodermic needles were contributing to the transmission of HIV infection. Clean needles, those who dared to break with convention began to assert, might do for addicts what condoms could do for the interruption of the spread of AIDS through sexual contact.[31] Despite the urgency of AIDS prevention, proposals to make sterile needles available, even on an experimental basis, met with strong opposition from law enforcement officials and drug-abuse treatment professionals as well as from

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articulate residents of the ghettos who viewed such programs as nothing less than tacit approval of genocidal drug use.

In New Jersey, New York, and San Francisco, modest proposals for programs through which addicts would exchange used needles for sterile ones were thwarted. It was only in 1988, after more than two years of struggle, that the state of New York granted New York City permission to undertake a very small experiment,[32] a decision made under the shadow of epidemiological findings that revealed the extent to which black and Hispanic women of childbearing age who were either drug users or the sexual partners of drug users were infected with HIV.

The limits imposed on education by social conservatism and timidity have been the target of repeated reformist assault. Gay leaders, advocates of civil liberties, the liberal media, the Institute of Medicine, the National Academy of Sciences, and the surgeon general have all in one way or another indicated the folly of such self-imposed constraints on the struggle against AIDS. Passionately they have tried to demonstrate that however discomfiting direct education of drug users or gay men might be, the alternative is far grimmer. But there are other limits on education that do not stem from political resistance and that will not yield to the force of political wisdom informed by the exigencies of the AIDS epidemic. These are limits imposed by the inherent difficulties that always confront efforts to motivate individuals to alter basic behaviors, which, no matter how ultimately dangerous, are deeply rooted in biological and psychological pleasures and often reinforced by cultural as well as social dynamics.[33]

However effective education has been[34]—longitudinal studies of largely white middle-class gay men have shown remarkable changes in behavior—much remains to be done, especially with adolescents and with intravenous drug users and their female partners, who are mostly poor, black, or Hispanic.

That more innovative and intensive anti-AIDS campaigns will be necessary in the next years is not a matter of dispute, though conservative resistance to the public funding of efforts directed at gay men and drug users will doubtlessly hinder such undertakings. Such efforts must entail much more than the need to inform. Though pockets of ignorance about the risks of HIV transmission remain, the challenge is not primarily cognitive. It is psychological, social, and

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cultural. To limit the spread of HIV infection will require a profound transformation in the way men, women, and adolescents choose to behave in the face of risk to themselves and those with whom they have sexual relations or share drugs. Involved will be an effort to force the pace of cultural change.

The behavioral goals of education are clear and deceptively simple. Those who are uninfected will have to insist that condoms be used in sexual intercourse with partners whose HIV status is uncertain. Some will choose not to have intercourse, under any circumstances, with the infected. Uninfected addicts will have to give up the ritual of needle sharing. The most difficult changes to foster and sustain over time will be those that impose restrictions and imperatives on individuals who are already infected. Their motivation will be weaker than that of persons who can still protect themselves. They will have to warn their sexual partners about their HIV status even at the risk of rejection. And they will have to give up pleasures—some more difficult to yield than others. Among the most difficult to yield will be the option of childbearing. In each case the individual calculus of personal risk will conflict with the collective calculus of public health.

A CULTURE OF MORAL RESPONSIBILITY

Only a cultural transformation can affect the private choices that will determine the future of AIDS in America. Impeding that transformation will be the psychological capacity for denial despite dreadful situations, moral indifference, and the social factors that give rise to and sustain patterns of behavior linked to the transmission of the AIDS virus—most critically the poverty that is at the root of intravenous drug use and teenage pregnancy in America's ghettos. Without an assault on the socioeconomic roots of those behaviors linked to the spread of HIV infection, emphasis on the importance of a culture of responsibility and restraint is bound to have only limited impact.

In the face of the enormity of the challenge AIDS poses for public health, what is to be done?

Through education freed from the strictures of moralism and conveyed in forceful and imaginative ways, public health officials can disseminate not only knowledge but also an appreciation of the moral claims imposed by the threat of HIV infection. By demanding

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that no drug user in search of treatment be denied access to care, they can demonstrate that social neglect is incompatible with a vigorous campaign against AIDS. By undertaking bold experiments, including needle-exchange programs designed to reach drug users uninterested in or refractory to treatment, they can underscore the willingness to place the prevention of HIV transmission above the dictates of convention. By promoting confidential as well as anonymous screening programs that reach out aggressively to those in need of testing to encourage the adoption of responsible behavior, officials can advance public health while simultaneously protecting the privacy of those who come forward. By defending the social rights of the infected, they can create a climate of trust among those who are vulnerable to acts of discrimination. By creating contact notification programs, they can underscore the public commitment to warning those who might not otherwise know they have been exposed to the AIDS virus. And by supporting carefully delimited legislation to control those who are infected but who recklessly or maliciously place others at risk, they can establish the moral priority of protecting the public's health as a social norm.

Each of these measures, some with greater impact than others, will contribute to the interruption of the spread of HIV infection. But it is as an ensemble that these measures will make a contribution to the emergence of a culture of responsibility.

Public health officials cannot create such a culture; they can only facilitate its development by promoting wise public policies to create the social conditions within which it can emerge. Ultimately, a culture of responsibility must take hold and be reinforced among those at risk for acquiring AIDS if it is to shape their private acts. It cannot be imposed upon them from above.

In the end the struggle against AIDS will be waged at a popular level by ordinary adults and adolescents as they seek to carve out private lives and intimate relationships in the face of a lethal biological challenge.

In the seven years since the Centers for Disease Control first reported the cases of disease that we have come to understand as the result of the silent spread of HIV infection, we have learned a lesson of some irony: the protection of the public's health is dependent on respect for privacy. Guarantees of confidentiality must be rigorous. Invoking the authoritarian tradition of public health may do more to

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damage the struggle against AIDS than a more modest exercise of that authority would.

We must learn another, more difficult lesson. It will be especially difficult to those who are committed to an open, pluralistic perspective on the role of moral values in a liberal political community. Precisely because of the intimacy of the acts involved in the transmission of HIV infection, we must develop a public culture that defines morally acceptable behavior.

With good reason, we become exceedingly uncomfortable with the prospect of passing moral judgment on the most intimate decisions made by consenting adults, on the decisions made by women about procreation. Oppressive moral codes, sometimes enforced by the state, have so recently been the target of liberal reform. We must, however, not permit the specter of legal moralism to paralyze us. The dread of moralism provides no excuse for evading a discussion of the moral responsibilities imposed by the behavioral nature of HIV transmission.

On the eve of the AIDS epidemic, the director of the Hastings Center, Daniel Callahan, wrote of the atrophy of the ethical culture of liberal society, of the truncation of the moral realm under the stress of privatism.[35] Like Robert Bellah in *Habits of the Heart*,[36] Callahan decried the primacy of America's "first language" of individualism: "What we have not had until recently is cultures that have systematically tried to forswear communal goals . . . that have served to sanctify the morally autonomous agent as the cultural ideal. Can that kind of culture survive hard times?"[37] This is the question AIDS poses for us as both a political and a social community.

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Michael Kirby

AIDS and Law

AIDS IS HARD; hard on the patients who learn the grim news; hard on the health-care workers, who have only a limited armory of therapies and no vaccine or cure in sight; hard on the scientists, working at the edges of knowledge, always under the pressure of a major catastrophe affecting millions of people in virtually every land; hard on lawmakers struggling to bring the cumbersome, imperfect machinery of legal control to bear effectively on intimate personal behavior, which must be modified quickly if the spread of the epidemic is to be slowed. And prejudice and hatred, fueled by fear, are always close at hand.

There are limits on what the law can and should do in response to AIDS. It never ceases to surprise me how otherwise intelligent people (including some lawyers) assume that when society has a problem, all it needs to do is make some new law and the problem will be solved. They assume that people will modify their conduct to avoid criminal punishment or civil liability.

But obedience to a law, even if everyone is familiar with it, is not certain and cannot be assumed. The law may entirely miss its mark because of its ambiguity or sanctions that cannot be enforced. Want of resources, discriminatory prosecution, or imprecise, ineffective design of the enforcement mechanisms frequently torpedo a law

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which looked fine when first made by the legislator, bureaucrat, or judge but just did not work on the streets.

And then many laws are honored in the breach. The world's societies are overburdened with them. But nobody seems to worry very much about all the communities that are churning out new laws and failing to provide the institutional means to bring old law into harmony with widespread social change.

Even if a new law is well written, precisely and accurately targeted, widely known and generally respected, there is still no guarantee that it will operate on human behavior at the critical moment when its effectiveness counts most.

A recent Australian report is an examination of behavioral change in response to the AIDS epidemic.[1] The authors list the factors they have found influence change. The first is direct knowledge of someone who was sick or who has died as a result of infection with the human immunodeficiency virus (HIV). The second is barriers militating against safe behavior. Laws may discourage people from approaching governments or health services or from acquiring condoms for "safer sex" and sterile equipment for intravenous drug use. The third factor is the use of alcohol and other drugs in sexual and presexual situations. The fourth is the relationship of the subject to his or her sexual partners. Negotiating safer sex with regular partners was found to be much more difficult than with casual partners. The fifth factor involves psychosocial characteristics such as self-image and self-confidence. The sixth is a person's knowledge about his or her HIV infection status. The seventh factor is age: younger and older individuals have demonstrated more difficulty in adapting to essential behavioral change than those between the ages of twenty-five and forty-five.

In a number of the Australian states in which the survey just mentioned was conducted, legislation had been enacted making it an offense for a person who knows that he or she has AIDS, or who has been exposed to HIV, to have sexual intercourse with another unless, before that intercourse takes place, the other person has been informed of the risk of contracting the disease and voluntarily agrees to accept that risk.[2]

Concern about compliance with that law, and fear of prosecution for the breach, would generally be the very last thing on the minds of individuals approaching potentially dangerous sexual activity. The

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marginalized groups at greatest risk of AIDS and HIV in societies such as Australia and the United States already face various legal and social disadvantages. For most of them, the enactment of laws against AIDS would be regarded as just another obstacle to be negotiated in life's journey in pursuit of their particular version of happiness. Prostitutes, intravenous drug users, and homosexual and bisexual men are no strangers to social prejudice, often reinforced by punitive laws.

THE CRITERION FOR ACTION

Our objective in proposing or making new laws on AIDS must be to contain the epidemic. The Australian health minister (Dr. Neal Blewett) has stated clearly his criterion for AIDS-related measures. I take it as my text. It is:

> Whether it will or will not impede the spread of the disease, whether it will be productive or counter-productive in containing the dissemination of the virus, any action, however well intentioned, which impedes efforts to monitor, contain and assess the spread of the disease should be rejected.[3]

Reflect for a minute on the laws and policies adopted to cope with earlier epidemics. They lie in the history books as warnings to us about human pain and cruelty but above all, about general ineffectiveness. The best known of the administrative measures of earlier times, quarantine, is said to have been developed in Italy, at Ragusa, during the second half of the fourteenth century. Such measures were followed by isolation, temporary removal of suspects, the creation of plague barriers, the use of purifying fires in public places, and vicious actions against minorities who were already stigmatized by factors other than disease.[4] King Philip of France ordered the extraction of the tongues of all blasphemers. He believed, ever so sincerely, that blasphemy had brought the bubonic plague on his country. Modern counterparts spring to mind. In epidemics lepers and Jews were often the targets of official action prompted by public opinion, which had been stimulated by myth and prejudice. Leprosy trials to establish a particular category of infection were well known in earlier centuries. Reporting, incarcerating, disenfranchisement, privation, and deprivation of civic rights have been the usual legal companions of

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infections over the centuries. As late as 1832 in Paris, numberless innocent people stricken with cholera were lynched by fearful mobs.

In this age of computer science, space flight, biotechnology, and nuclear fission as AIDS comes upon us, can we do better than in the past? Only if we appreciate several fundamentals. We must candidly acknowledge the limited function of law as a response to AIDS and realize that laws will not be effective until they are based on good data concerning the nature of AIDS, its modes of transmission, and the precise conduct that encourages or diminishes transmission. We must recognize the counterproductive effects of laws and practices that limit the ready supply of condoms or impede the use of sterile needles by intravenous drug users.

We may decide that we prefer a society that clings to the ideals of sexual chastity to a society that teaches young school children explicitly about the dangers of AIDS and facilitates the provision of condoms to all who want them. We may prefer to concentrate on the "war on drugs" rather than on legalizing the exchange of sterile for used needles or the provision of bleach to users at risk. But we should do so with our eyes open.

HUMAN RIGHTS CONTEXT

In a review of AIDS and the law it is easy to overlook the human-rights context. Many lawyers and lawmakers busy in their offices, courtrooms, and legislatures exhibit an impatience with talk of human rights. A frightened community concerned about the spread of a dangerous virus may be very impatient indeed with such talk. But any review of law on this subject which ignores the human-rights dimension will be empty of principle. It will overlook fundamental values and run the danger of losing its way in a mass of parochial detail. A sensitivity to human-rights principles provides us with the mileposts by which we may find our way across the dangerous landscape of burgeoning laws made to deal with AIDS.

Many of these principles appear in international treaties and customary international law yet may not be enforced in national courts. But it is useful to remember that there are abiding basic values which have been formulated by leading philosophers and lawmakers over the centuries. In the face of the risks of ill-considered actions

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resulting from panic, it is important to keep our eyes fixed steadily on the basic values which civilized communities accept.[5]

There is no human right to spread a deadly virus, whether knowingly or recklessly. The right to the protection of life is primary. But it must be achieved with the protection of other relevant human rights, such as the right to privacy, the right to liberty and security, the right to freedom of movement, the right to marry and found a family, the right to work and be educated, and the right to freedom from inhuman or degrading treatment or punishment.[6] We must harmonize our legal responses with these fundamental values, which will endure even after the AIDS peril has been overcome.

THE PERILS OF GENERALIZATION

Now, let me speak frankly of the limitations of law. First of all, law is always local in the sense that its operation is limited to a particular legal jurisdiction. Approaches to epidemic control vary enormously according to the political system in operation—how responsive it is to popular opinion, how authoritatively it can deal with problems.

Furthermore, law does not exist in isolation. It is part of a mosaic of social regulation. It is shaped by the institutions which make it and on which it must operate. The felt needs for law depend on the perception (and actuality) of the size and nature of the problem being addressed. Statistics from the World Health Organization (WHO) show the wildly uneven distribution and differing patterns of AIDS at this stage of the epidemic in various countries.

Finally, whereas medical and other scientists dealing with the human body work on phenomena that are universal and unvarying, the legal systems around the world are fundamentally different. Two systems predominate. One of them is represented by the common law system, derived, ultimately, from England. It is substantially followed in most English-speaking countries. It lays emphasis on the role of the judge as an expositor of law. Even legislation enacted by elected legislators (or subordinate regulations made by administrators under delegated power) reflect the intended interaction of such legislation with judge-made law. The other major system is that of civil law, derived principally from France. In this system the rule of the judge as a lawmaker is important but less so. Codification by the legislature

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and general statements of the law by text writers are more common in countries of the civil law system.

The foregoing is to introduce what follows by words of necessary caution about the extent to which legal rules established to respond to AIDS in one jurisdiction may be adapted to the differing legal environment of another. At some points (as in international travel) domestic laws interact. They then affect foreign nationals. But for the most part, although the problem of AIDS is now global, the responses of the legal systems of the world depend on local institutions and legal environments.

WHO contributes to understanding the commonality of legislative responses to AIDS by the publication of tabular information on legal instruments dealing with AIDS and HIV infection.[7] A circular is published regularly in two parts. One surveys the United States, the present epicenter of the epidemic, by reference to legislative instruments, federal and state. The other deals with instruments reported from other jurisdictions around the world. These reports are indispensable. Although they omit judge-made law and much official practice and policy that is important in matters of public health, the WHO reports provide a conspectus of law enacted in the legislatures of countries operating according to common law.

Laws have been enacted quickly in many countries to provide for the screening of blood products and the notification by medical practitioners of suspected or confirmed diagnoses of AIDS. A growing number of jurisdictions is introducing requirements for compulsory screening of identified groups, particularly immigrants and prisoners. It is not my intention to collect and analyze these laws. Instead, I wish to give a general look at the laws on AIDS, so that some notion can be derived of the way in which lawmakers in many lands are responding to the epidemic.

CRIMINAL LAW

Since exposure to HIV infection may lead to AIDS, which is life threatening, it is a legitimate purpose of the law to endeavor to protect individuals, communities, and nations from the spread of the virus. Through their systems of criminal law, societies attempt to inculcate individual responsibility. Although criminal law operates imperfectly, it sometimes has a symbolic value: it can state that

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conduct is punishable and hence is not approved by society. Various theories exist to justify the stigmatization of conduct by criminal law. According to one theory, it is enough that conduct offends the moral sense of most members of society. This was a traditional basis for laws penalizing adult homosexual conduct in many countries, even though there was no complaining victim. But with the spread of HIV, there is a risk of serious actual harm to individuals. This would invoke the other goal underpinning criminal law: to protect the individual and the community of individuals from harm.

It is possible that in some places knowingly spreading HIV to another person—or being recklessly indifferent to whether by sexual or other conduct the actions of the individual will have that consequence—already amount to a crime under general provisions of criminal law. Depending on its terms and on the consequences of the act, such conduct might amount to murder, manslaughter, or assault occasioning grievous bodily harm.[8] Calls are now being made for the provision of specific criminal offenses by which, on conviction, courts may penalize the deliberate or reckless spread of this lethal virus.[9]

Responding to such calls, a number of states in Australia and the United States have enacted laws to provide a specific penalty in the case of unprotected sexual intercourse by an infected person. I have already mentioned the special law in New South Wales in Australia. That law does not prohibit an infected person from having sexual intercourse. It applies the law's sanction for failing to inform and secure the consent of the other person. The penalty for not doing so is a maximum fine of $5,000.[10]

This may seem a modest penalty for activity that may spread a potentially fatal infection.[11] In the state of Victoria, amendments to the Health Act were introduced in 1987 to provide a fine of up to $20,000 for a person who deliberately infects another with AIDS or any other infectious disease. In Idaho, an act of 24 March 1986 declared that "wittingly and deliberately exposing another person to the possibility of being infected" by a person suffering from AIDS or similar disease is unlawful. By an act of 7 January 1986, Florida made it unlawful for a person suffering from HIV infection to continue having sexual relations with another person unless that person had been duly informed of the risk of transmission of the disease.

All such laws should be seen as having a symbolic rather than a practical value. Clearly, the maximum penalty for the offense is

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inadequate. Proof and enforcement of the law would be extremely difficult. The offender may be dead or very ill by the time of the prosecution. Proof that it was he or she who caused the infection may be next to impossible. Moreover, such laws may have a counterproductive effect, even though unintended. If an element in such crimes is knowledge of one's own HIV status, the provision of such laws may actually discourage persons from taking the HIV test, particularly if there are provisions for reporting persons who prove HIV positive to the test, with personal identifiers that can be traced. The Australian survey I have mentioned shows that submitting to the HIV test may itself sometimes be a useful educational step in a course of behavior modification designed to promote self-protection and the containment of the AIDS infection. Criminal offenses, which have only a minor symbolic value and are rarely, if ever, prosecuted with success, may actually prove counterproductive because the only real effect they may have is to discourage test taking.

This is not the only area where AIDS and the criminal law intersect. For example, in a recent murder prosecution in Sydney, Australia, the accused contended that he had killed his wife because she admitted having had an affair and he feared that she had contracted AIDS from it and would infect the children. I suspect that we will see more defenses of this kind even though, objectively, there would be little rational basis for such suspicions. In numerous criminal cases, issues relevant to AIDS are now arising. Thus in England, the Queen's Bench held that fear of giving a blood sample so as to detect the presence of alcohol in the blood of a driver, allegedly on the ground of concern about contracting AIDS in the process, was not considered a reasonable excuse to justify the refusal.[12] Also in England, the Court of Appeal has reserved for the future the question whether fear of AIDS can justify a higher tariff in the punishment of a person convicted of rape.[13] In South Australia the State Supreme Court has held that the fact that a prisoner is suffering from AIDS is a consideration relevant to the determination of his or her sentence. This was justified with regard to the state of the prisoner's health, his health prognosis, and the likely loss of ordinary prison privileges because of isolation, consequent on the diagnosis of AIDS.[14] But not all Australian judges have taken the same view.[15]

In some jurisdictions constitutional guarantees of human rights will be invoked to protect the privacy of consensual adult sexual

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conduct. Recent decisions of the U.S. Supreme Court holding that states do not violate the federal Constitution when they punish homosexuals for consensual sodomy[16] and that Army regulations discharging homosexuals, as such, from the armed services[17] do not conflict with the Constitution suggest that constitutional limitations will not always play a large part in the United States in controlling criminal or other laws targeted to the spread of the AIDS infection, whatever the invasion of privacy or breach of other rights involved in them. On the other hand, recent decisions of the European Court of Human Rights show the utility of generally stated human-rights norms as weapons for striking down laws penalizing homosexuals as such. In the *Dudgeon Case*, Article 8 of the European Convention on Human Rights was successfully invoked against the United Kingdom with respect to such laws in Northern Ireland. That article deals with the guarantee of privacy. More recently, in the *Norris Case*, the Court invoked the same article to hold the Republic of Ireland in breach of Article 8 in respect to a complaint from Mr. Donald Norris, a campaigner for homosexual rights in that country. Ireland is now required by the convention to bring its law into harmony with the requirements of Article 8.[18] In half the Australian states, the law remains as it is in Ireland. Many commentators have urged the necessity of reform to reduce stigmatization and to promote effective AIDS communication to a major at-risk group.[19] But there is no operating constitutional or international instrument in Australia to stimulate change, and none appears to be forthcoming at this time.

QUARANTINE AND PUBLIC HEALTH

Quarantine laws are generally categorized as civil rather than criminal. However, they may impose restrictions on individual freedom which are as severe as penal laws. Sometimes they do so without the protections typically built into criminal process. Quite frequently quarantine laws reflect the oppressive attitudes that prevailed in more primitive times when quarantine was first developed.

So far, only the country of Cuba has provided a specific law to quarantine all persons with HIV infection. Such a law would be manifestly unjust, impractical, and ineffective in the most developed countries. The antibody test does not disclose all who are infected. It

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would be difficult, if not impossible, to provide resources to house, feed, guard, and isolate all such persons. The impact of withdrawing from an economy people with eight, ten, or many more years of productive contribution would be crippling. Moreover, when one considers how the virus is transmitted, the risk of the spread of the infection to the whole community remains small. Clearly, the target of laws and policies should be the behavior that spreads the risk, not the individual as such. Laws focused on individuals or groups may carry the risk of unjust discrimination or may be too heavy-handed in their operation. That is why a general policy of quarantine has been described, rightly, in my view, as a brutal and unrealistic approach to the containment of HIV.[20]

Nevertheless, calls for quarantine and identification of the infected have occurred.[21] They will become much more common as the infection spreads. In a number of jurisdictions, already existing powers of quarantine have been enhanced and made specific to include AIDS.[22] Fortunately, lessons have been learned from the ways in which communities earlier tackled syphilis, also a sexually transmissible disease that is potentially lethal. An English Royal Commission report in 1913[23] made the point that the public health objectives of identifying the infected, counseling them, and giving them such treatment as was available were more likely to contain the disease than were punishment and quarantine. As with syphilis, so with AIDS. Winning the support of those who bear the burden of infection and modifying their behavior is the strategy that offers most promise at this time, at least in developed countries.

Many jurisdictions have enacted laws to provide screening for the presence of HIV. None has so far provided for mandatory screening of the whole population. Most commentators have recognized this as ineffective. It is a grossly inefficient use of available public resources. Furthermore, it carries with it the risk of discrimination on a large scale.[24] Notwithstanding rational arguments against screening of particular groups in the community, numerous jurisdictions have provided for it. China, for example, has recently extended its compulsory testing to all foreigners who apply to live in the country for more than six months.[25] Many other countries, particularly those reporting a low incidence of AIDS and HIV, have drawn up similar laws.

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Legislation to screen for antibodies to the AIDS virus raises numerous legal issues:[26] whether the screening should be voluntary or compulsory, whether the screening facility should guarantee the tested person's identity, and whether those doing the screening should submit identified or purely statistical data to central record-keeping facilities. The concern about AIDS registers and data protection has now begun to attract the attention of both international[27] and national[28] reviews of this issue. Because of the risk of discrimination, if not immediately, then in the long term as the epidemic worsens, the anxiety about invasion of privacy adds to the anxiety about health.

The submission to screening does not in itself affect in the slightest either the health of the individual tested or the containment of the virus in the community. However, undergoing the test may encourage at least those found to be without HIV infection to modify their behavior and henceforth to practice safer sex and to avoid the sharing of blood and other practices so as to limit the cycle of the infection. Screening also provides the best possible data on the epidemiology of AIDS. For these reasons, I believe that anonymous screening and deidentified reporting should be encouraged. Some purists insist that even then consent of the donor should be obtained, but I do not agree.

The provision of facilities for counseling those undergoing the screening test for HIV was emphasized in a number of sessions at the Fourth International Conference on AIDS in Stockholm. One of the topics most hotly debated was whether a medical practitioner who knows that a patient is infected with HIV has an obligation to warn that patient's sexual partner(s) and if so, when. In circumstances of persistent refusal or failure of the patient to tell his or her partners, does a duty to other individuals and to public health override the duty of confidence owed the patient? Unless legislation is enacted to impose or relieve the medical adviser of liability to do so, such duty would, in common law countries, probably be worked out by reference to the laws of confidence and negligence.[29]

The law has dealt with various other public health issues that AIDS has raised. They include such matters as the closing of venues considered responsible for spreading the infection (e.g., bathhouses), the limitation of acupuncture for AIDS patients and of organ transplants from persons infected with HIV, and the tracing of sexual

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partners so as to provide them with counseling about exposure to HIV infection.

BLOOD TRANSFUSIONS

Early in the epidemic a major source of the spread of HIV infection was the blood supply. In developed countries, most transmission of the virus occurred before the problem of AIDS was generally known and before the antibody test for the presence of the virus was generally available. But even now, in a number of developing countries, inadequate resources are available to test blood products. This is just one of the many situations in which costs limit the effective response of developing countries to the impact of AIDS. Another is the prohibitive cost of treatments available, which even in richer countries must be rationed.

Numerous legal issues are raised by post-transfusion AIDS.[30] Many have concerned the liability of suppliers of blood products when they are alleged to have caused the infection of patients. A number of cases involving allegations of this kind have come before the courts in Australia. In one, an application for the identification of a blood donor was refused.[31] In another, an application to bring legal proceedings beyond the time generally fixed by law for that purpose, on the ground of delayed diagnosis of AIDS, failed.[32] In some jurisdictions, provisions have been urged for a special fund to indemnify those who have acquired HIV or AIDS from blood transfusion.[33] In such cases care must obviously be taken not to discriminate between those who have acquired the infection from transfusion rather than from, say, sexual conduct which was not at the time unlawful or known to be dangerous. Such a distinction could perpetuate unjustifiable discrimination among patients with AIDS, all of whom suffer in the same way. All of them need the support of a caring society.

MARGINALIZED GROUPS

One of the most tricky problems AIDS presents to lawmakers is that the groups initially infected with the HIV virus in developed countries were already stigmatized and, in some sense, socially outcast.[34] I refer to homosexual or bisexual men, intravenous drug users, and prosti-

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tutes. In Australia, public opinion polls suggest widespread support for mandatory testing of such groups. A 1987 survey showed 90 percent support for compulsory testing of homosexuals, 86 percent for testing all immigrants entering Australia, 83 percent for testing prisoners in jail, and 57 percent for testing tourists entering the country.[35]

Democratically elected governments, under the pressure to be seen to be doing something effective in the face of a major epidemic, may be tempted to legislate against particular groups. Migrants, prisoners, drug users, and prostitutes, in particular, lack an effective voice to dissuade lawmakers from making laws discriminating against them. It is therefore important for those with knowledge about the science of lawmaking to remind lawmakers of the dangers of unjust discrimination and the probable ineffectiveness of mandatory testing of such groups. To test migrants but not tourists would seem unjustifiable, as the latter, rather than the former, may have greater exposure to AIDS. To test prisoners without making administrative arrangements for their care if found to be HIV positive is pointless. Yet in prisons around the world (including Australia), compulsory testing is now increasingly occurring. To provide for testing of prisoners and not to provide for condoms and bleach, at least for the control of the spread of infection by intravenous drug users is irresponsible.[36]

In a survey conducted for the National Health and Medical Research Council of Australia, it was disclosed that about 12 percent of the men in the sample admitted to engaging in homosexual behavior during their lives.[37] This is a lower figure than Kinsey reported in 1948 in the United States (37.9 percent). The actual proportion might well be higher than the Australian survey suggests. The possibility of sexual activity in crowded prisons, where normal sexual outlets are impossible, must be expected. In many countries public acceptance of this fact is growing.[38] The sexual revolution in developed countries has brought with it an understanding of human sexuality and a willingness to face it candidly and to discuss its consequences, including AIDS and HIV, publicly.

This realism may, in due course, produce an important legal revolution concerning intravenous drug users. The reports to the Stockholm Conference on AIDS made it plain that in the United States and Europe heterosexual intravenous drug users are now a rapidly growing proportion of those with HIV infection (estimated to be 25 percent in the United States and 30 percent in Europe).[39] In a

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number of jurisdictions, this fact has led to the lawful provision of sterile syringes in an exchange program designed to curb the spread of HIV. An Australian report suggests that more than one in every ten returned needles in the inner city of Sydney is infected with HIV. This constitutes a "substantial increase" in the apparent spread of the virus among intravenous drug users.[40] The figure is rising quite rapidly. The introduction of syringe-exchange programs requires a degree of political courage, especially when so many countries are concerned about the rise in use of narcotics and other drugs. These new programs also represent recognition of the fact that the present legal response to drug control is failing. Increasingly, countries are willing to consider (or at least to experiment with) treating the problem as one of public health. A discussion paper issued in Australia in February 1988 included for the first time a review of options designed to control what was described as "the second AIDS epidemic" (the spread of HIV through the sharing of syringes and sexual intercourse to the general community).[41] Editorials turn up now in a number of Australian newspapers suggesting the need to provide heroin and other drugs to intravenous drug users as part of a strategy to prevent the risk of the spread of the AIDS virus into the population at large. Illegality and the covert supply of drugs tends to promote this risk.[42] This is itself a most remarkable development. It reflects the growing recognition of the seriousness and extent of the problem of AIDS. A drastic problem may necessitate drastic solutions. It may concentrate the mind on those measures most likely to be effective.

OTHER ISSUES

Numerous other issues require mention in any review of the impact of AIDS on the law. They include:

- The provision of laws prohibiting discrimination against people with HIV or AIDS whether in employment,[43] schooling,[44] housing,[45] social security, or otherwise. There are areas where the law may have a positive role to play. Necessarily, the law's power to change deeply felt and long held public prejudices is limited by the considerations already mentioned.

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- Family law, which may be affected, for example in legal systems that provide for dissolution of marriage on the ground of matrimonial fault such as adultery.[46] Particular issues of child abuse, the rights and liabilities of sexual partners, and the position of families devastated by the loss to AIDS of an income earner all need consideration. An interesting consequence of the introduction of laws requiring premarriage tests for HIV in some jurisdictions of the United States was reported in Stockholm: applications for marriage licenses fell by 60 percent.[47] This drop demonstrates the need for more careful consideration in the design of such laws.

- The regulation of insurance and the extent to which insurers may seek to protect themselves from unjustifiable liability while requiring policy holders to answer questions or undergo screening for HIV.[48] In the absence of publicly funded health care, entitlement to the protection of private insurance may be critical to guaranteeing a tolerable quality of life for the infected and sick. Questions about whether a person has submitted to screening, for HIV or for sexual orientation, for example, might be unfairly discriminatory. So might prohibitions on the provision of insurance to particular groups, given that it is behavior and not the members of a group that puts a policyholder at risk.

- The neuropsychiatric aspects of HIV infection and the question whether dementia will provide justification for compulsory screening of employees in some occupations, about which concern has been expressed. A number of airlines are now requiring flight and cabin crew to submit to HIV tests, ostensibly on this basis. A WHO committee has questioned the justification for such tests. It has pointed out that mental impairment is likely to show up in advance of other symptoms, thereby removing the justification for universal screening with its serious danger of discrimination.[49] It is mental impairment, not the presence of HIV, that should be the subject of such investigations.

- Reports of the first tests of AIDS vaccine made to the Stockholm Conference on AIDS in June 1988. Vaccines present serious issues for the legal liability of the individuals and corporations involved in such tests. In some jurisdictions, judge-made decisions and legislative provisions have had the effect of impeding or slowing vaccine

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development.[50] Given the dimension of the global problem of AIDS and the urgency of providing an effective cure and vaccine as quickly as possible, consideration will need to be given to such matters as the protection of drug companies and the compensation of any who suffer from this important work.[51]

- Finally, the likelihood, in present circumstances, of large numbers of persons dying from AIDS, which has called attention once again to the issue of euthanasia and the need for respect for the terminally ill.[52] Sadly, hysteria can generate pain for the dying and the grieving. In New South Wales, for example, regulations require that a person known to have AIDS or reasonably suspected to have suffered from it should, at the time of death, be placed in double plastic bags, heat sealed, with the words "Infectious Disease —Handle with Care" placed on the body in letters of prescribed color and height.[53] Obviously, this procedure has exacerbated grief in some situations. It betrays the right of a deceased person not to disclose the nature of his or her illness. There is no scientific basis for the regulation. AIDS is not transmitted by handling the body of a person who has died in this way. The regulation was, I regret to say, nothing more than a response to a trade-union demand grounded in irrational fear. We will see many more such laws before this epidemic is over.

CONCLUSIONS

This last comment calls attention once again to the need to base laws on facts. From a recognition of the limited capacity of the law to promote the necessary behavior modifications, some consequences follow for the containment of HIV and AIDS.

In the hard battle against AIDS, some things, at least, have fallen out right. We are fortunate, for example, that this epidemic has struck at a time when we have the World Health Organization to mobilize the international community. We also have the new tools of molecular biology to identify the virus. We have the modern means of communication to spread the vital educational message rapidly. In developed countries, we have greater candor, which has, in varying degrees, accompanied new attitudes toward human sexuality.[54] Such attitudes will be helpful in combating stigmatization and in promoting frank

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instruction, including to the very young, concerning the modes of transmission and means of protection. We have, in some places, a healthy new willingness to think radically concerning the groups most at risk, not least for the protection of the rest of the community. We also have a growing knowledge about the science of jurisprudence: how to make laws which are just and efficient in securing their objectives. It is this knowledge which brings a realization of the limits of what can be achieved by the law in epidemic control.

An Australian judge once said that the law "limps after medicine . . . at the rear of the line."[55] For the health of society and the practical containment of AIDS and HIV, that is where I would generally keep the law for the present. Overenthusiasm in enacting laws on AIDS may make some people feel better, but such laws will have precious little impact on controlling the spread of the epidemic. For the time being, control in countries like Australia and the United States depends primarily on community and individual education. That may seem a strange conclusion for a lawyer to reach. But I am sure that it is right.

The only vaccine we have at the moment, or are likely to have in the foreseeable future, is knowledge, as the Swedish Minister for Health said at the International AIDS Conference in Stockholm.[56] This is why legal regulation should at present be addressed primarily to facilitating public education, providing condoms made to a reliable standard, and making anonymous HIV screening readily available. As has been pointed out, such screening may sometimes be the first step on the road to self-protection and the protection of others.

The report of the United States Commission led by Admiral Watkins (which coincided with the Stockholm AIDS Conference) was an important reinforcement of the leadership earlier given by United States Surgeon General Koop. The report emphasized the need, paradoxical though it may at first seem, to accompany laws and policies on AIDS with the provision of protection against discrimination of those who are infected. The lesson is there from the earlier legal regulation of syphilis, when it was incurable and often deadly. Attempts to deal with syphilis punitively, by stigmatization, mandatory contact tracing, and the rounding up of prostitutes,[57] provided no effective protection for society. And it involved great injustice. Injustice in combating AIDS might be tolerated by some. Many in the groups presently most at risk in developed countries face the prospect of

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further stigmatization. They contemplate greater injustice with resignation and an anger controlled by knowledge born of long experience. But inefficiency in controlling the spread of HIV is unforgivable. At risk is nothing less than the health of millions of people.

One day AIDS may be just a footnote to human history. It may become like all the other epidemics which have come and gone, carrying off their anonymous millions.[58] I hope that it will not be said then, as it so often has of the past, that the suffering of epidemic was accompanied and even exacerbated by inefficient and unjust laws. This time we must do better.

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June E. Osborn, M.D.

Public Health and the Politics of AIDS Prevention

THE PRESENT INADEQUACY of political strategies to deal with the AIDS epidemic is a concern around the world but nowhere more than in the United States. Politicians there have dealt haltingly with AIDS issues thus far, even when clear advice and consensus have been available from such credible sources as the Institute of Medicine, the National Academy of Sciences, and the Presidential Commission on the Human Immunodeficiency Virus Epidemic. This hesitancy is potentially disastrous, given the magnitude of the AIDS threat, and reflects both cultural confusion and inequity, brought into relief by the ferocity with which the epidemic has attacked the fringes of American society. Clearly, there has been a failure of political will in proportion to the need for public understanding and compassionate response.

Underlying the misestimation of the AIDS menace is an assumption that science and technology, if applied with sufficient diligence, can eliminate all threats to public health. In the decade preceding AIDS, the crises presented by legionnaires' disease and toxic shock syndrome were dealt with efficiently and capably by public health officials and scientists, and early in the AIDS epidemic it was tempting to assume that it would be only a matter of time until similar victory could be declared.

Analysis of the new virus and its pathogenesis, however, revealed that the biology of the host-virus relationship is exceptionally com-

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plex, that vaccines and cures for AIDS are not imminent, and that education for prevention of virus spread through behavior modification will be the sole available weapon for years to come. With no quick technological fix, the public has become uneasy, and its response filled with conflicting currents. Some people say that scientific ineptitude explains the absence of a vaccine, while others propose that scientists have been malignly sluggish in their efforts due to bias against the socially peripheral groups whose members comprise a large proportion of the number of persons with AIDS.

This public misappreciation of the products of scientific study is particularly tragic since the data are very clear: the human immunodeficiency virus that causes AIDS and related disorders of the immunologic and nervous systems is spread by restricted modes of transmission—solely by sexual intercourse, by injection of substantial quantities of infected blood, by sharing of drug-injection apparatus, by transplantation of infected organs, or by birth to an infected mother. Once blood and organ donations are made secure, the involvement of voluntary, consensual behavior in all remaining modes of transmission means that, despite the lack of a vaccine, epidemic containment is possible through education for prevention.

That fortunate fact makes AIDS very different from influenza or measles and sets a distinctive public health agenda. For the first time in history, in the face of an ominous epidemic pathogen, the insights from rational scientific inquiry allow for individual avoidance of threat and for a coherent, focused, humane societal response.

Nevertheless, much of the political discussion to date has been formulated on the basis of inappropriate analogies, invoking past experience with very different public health problems such as plague and polio. Mandatory or coercive approaches to populations at risk dominate legislative dockets despite the nearly unanimous warnings of public health experts that such draconian measures would do more harm than good and, if pursued, would drive underground the very people at risk and most in need of education and counseling. Indeed, policies of quarantine or isolation are no more relevant to HIV than an onslaught of cavalry would have been in the tactical landscape of Vietnam. Furthermore, urgent recommendations that antidiscrimination measures are of the utmost importance to facilitate voluntary compliance with public health interventions have thus far gone unheeded.

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A particularly ominous political feature of the AIDS epidemic is the shadowy terrain of sexual behavior, illicit drug use, and procreation in which HIV is found, for nowhere is educational intervention more awkward. Sexuality is characteristically off-limits as a topic for frank family discussion (even though television programming is saturated with sexual innuendo), and sex education in the schools is a matter of hot debate. American ambivalence on these topics is so profound that there is a paralyzing animus against contraceptive advice for adolescents despite both a massive epidemic of teenage pregnancy and a startling prevalence of abortion as a mode of reproductive control. Finally, a broadening array of sexually transmitted diseases had been undergoing epidemic increase well before the emergence of AIDS.

Along with sexual mores, drug use is central to the AIDS epidemic, but as a political issue it is even more problematic. Whereas sexually transmitted diseases are at least acknowledged to be public health problems, illicit substance abuse and addiction have been approached as legal matters for which punitive responses are not only appropriate but sufficient. The advent of AIDS actually coincided with an escalation in severity of the drug epidemic, which was countered with a strident "war on drugs" but a contradictory lack of treatment facilities.

PATTERNS IN THE WORLDWIDE EPIDEMIC

The foregoing discussion deals with the U.S. epidemic, but AIDS is a global problem; and despite the diversity of peoples, recurrent themes are striking in public health policy debates around the world. Of 166 countries in the World Health Organization (WHO), 142 have reported one or more cases of AIDS and 151 have acknowledged their involvement in the HIV epidemic to the extent of initiating concrete collaboration with the WHO Global Program on AIDS in support of their own national AIDS programs. Common elements in all these countries are the presence of the virus, an awareness of its long, silent incubation period and its relationship to sexual behavior and drug use, and an epidemic of fear that threatens to distort the agendas of public policy and public health.

There are distinctive variations in initial patterns of the HIV epidemic, however, and they are worth noting since they explain, in part, differences in regional and rational political responses. Jonathan

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Mann, director of the WHO Global Program on AIDS, has described the worldwide epidemic as being of three general types.

Pattern I, by his characterization, involves a preponderance of gay and bisexual men, along with a variably prominent cohort of intravenous drug users and persons infected through contamination of the blood supply. This pattern is found in most of the major Western industrialized countries as well as Australia. Attitudes toward homosexuality and illicit drug use dominate the politics of response in these countries, as does a strong tendency to deny the occurrence of heterosexual transmission, even though that is well documented and growing in importance.

Pattern II is seen in the Caribbean and in large areas of sub-Saharan Africa, and differs in that heterosexual intercourse has been the dominant mode of HIV transmission from the start. Blood transfusion, the reuse of contaminated needles, and intravenous drug use contribute in variable degree, but homosexuality generally plays a minor role in this pattern.

Pattern III is the designation Mann uses for countries in which few cases of AIDS, or even of HIV infection, have yet occurred. Most of the Eastern Hemisphere falls into this category, as do a number of the eastern European countries. These areas have an obvious opportunity for preventive public health measures, but they also might be tempted either to deny their involvement or to react categorically and repressively against persons perceived to represent risk.

For present distribution patterns in the world, see the map on page 151.

The apparent variation in types of epidemic pattern may well be short-lived. The virus of AIDS is so widespread that it is unlikely ever to be eradicated, and as time passes the fact that it can be transmitted by sexual intercourse of most sorts is likely to broaden its distribution in Pattern I countries and to increase its representation in Pattern III areas. Recognition of this potential for epidemiologic evolution is crucial, for if short-term perceptions of the problems posed by AIDS determine the political response and options under consideration, victimization can replace compassion and crucial preventive opportunities may be missed. Furthermore, educational efforts, being perceived as relevant only to "others," will miss their mark.

As a particularly tragic example of such misperception, the American black community was lulled for several years by the widely held

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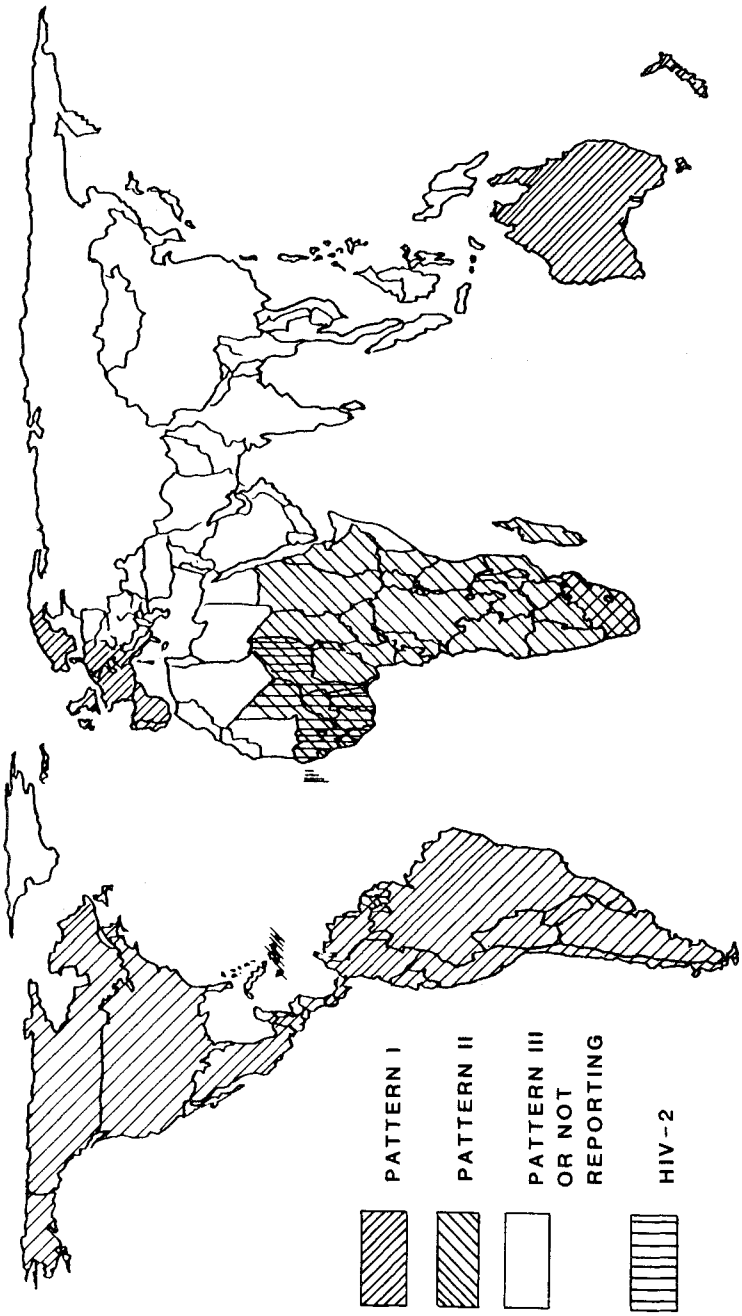

Present Distribution Patterns of AIDS in the World

Map courtesy of Barbara O. de Zalduondo

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assumption that AIDS was a "gay white man's disease"—whereas in fact twice as many blacks (and Hispanics) have AIDS as would be predicted from their numbers in the population, and their involvement derives from a full range of risk behaviors.

American heterosexuals, particularly women, persist in ignoring the risk of multiple sexual partnerships despite the fact that the male-female ratio among infected persons is dropping rapidly. (In contrast to a ratio of 11:1 for AIDS cases, antibody prevalence studies show the national infection ratio to be only 3:1, and the virus is nearly equally present in male and female volunteers from the New York City area, where HIV has probably been present for the longest time and therefore has had a chance to equilibrate.)

POLITICAL DYNAMICS IN PATTERN I COUNTRIES

Regardless of which epidemic pattern describes present circumstances in a given political environment, the voluntary and consensual nature of HIV transmission must be a central consideration in public health programs designed to curtail its spread.* Aside from issues of blood supply and related matters, the dominant public health agenda items under contemporary political discussion are general and targeted education for prevention, counseling and testing of persons at perceived risk of HIV infection, and intervention to interrupt spread through illicit drug use.

In each context, the tone and style of the effort determines the outcome. For example, pejorative words and discriminatory backlash diminish the likelihood that persons whose behavior puts them at risk for AIDS will identify with group designations and respond to

*Where blood supplies are not secured, that assertion cannot be made so categorically, and the contribution of HIV testing in that regard cannot be overstated. Testing of blood donors is mandated in the United States and in most industrialized countries, and the risk of HIV infection from blood and blood products has been reduced dramatically, although not to zero. Even in the context of blood donation, however, donor education for purposes of self-deferral when risk factors are recognized is a critical part of the overall strategy of protection.

With recognition that transplantation of organs, tissues, or cells also carries a risk of HIV transmission, those programs are also being brought under the same mandate. The screening of biological materials constituted an important arena for political activity during the first years of the AIDS epidemic, but the present discussion will not deal further with that aspect of the AIDS epidemic.

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educational initiatives or testing for HIV infection or antidrug programs.

Targeted Education

Education of the general public and of targeted populations at special behavioral risk has been the primary focus of the public health response in most industrialized countries of the world, and it is the nearly unanimous consensus of public health professionals that it embodies the key to epidemic containment. Nevertheless, concerted efforts at public education have received reticent, if not reluctant, attention in the United States thus far. Given the topics to be dealt with, some degree of political hesitancy is predictable, for homosexuality, sexual spread of HIV involving multiple sexual partners, needle sharing during drug use, and prostitution are not usually tolerated as matters of discourse.

Nonetheless, the diverse cultural barriers present in western Europe, Canada, and Australia yielded almost immediately to the awareness that those thorny issues were at the crux of HIV control. Their responses took the form of sustained public educational efforts deploying many media, and they spread the dual message that HIV was difficult to transmit but that specific behaviors could place persons at risk. Analysts have questioned the effectiveness of public education programs, and many initial media efforts in Australia and Europe were suboptimal and in some cases simplistic. However, the level of public anxiety is substantially lower in countries where systematic public education has been undertaken, and the profound silence of U.S. leadership has been difficult to justify over several years of widening epidemic spread.

The goals of general educational activities are appropriately limited to diminution of fear and delineation of risk behavior. Accurate information about HIV will provide an antidote to public panic and thus contribute to a tolerant, perhaps even a compassionate, social climate. Education alerts persons at risk for HIV infection that there is critical information to be sought to protect themselves and/or their loved ones.

The U.S. political apparatus has proved nearly refractory to urgent calls for such concerted messages about AIDS. Whereas the United Kingdom and Australia began distribution of general informational brochures to households within months of the first recognized AIDS

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cases, a comparable effort in the United States was delayed until seven years into the epidemic. After several false starts, Congress mandated a national mailing of AIDS information and a target date of October 1987 was set by the U.S. Public Health Service to produce a brochure as the cornerstone of "AIDS Awareness and Prevention Month." Even though the month was duly declared, the accompanying brochure did not circulate until eight months later. There is no clear record of the debates within the federal government, so the political dynamics of such delay are only conjecture, but the administration was reluctant to discuss openly the behaviors that put persons at risk and a vehement minority proclaimed that to make any effort to warn about unsafe sexual practices in order to delineate "safer sex" activities between gay men would be to condone homosexuality.

So potent was the political threat perceived to be that when Senator Jesse Helms of North Carolina introduced an amendment that seriously threatened safer sex education by agencies that received federal funds, only two senators had the political stamina to vote against the amendment. While the effect of the Helms amendment was subsequently modified by further senatorial maneuvering, the manifest power evinced by Senator Helms remained a lurking threat throughout the remainder of the debate leading up to the AIDS bill that finally passed in late 1988. With respect to the brochure that finally emerged as a general U.S. mailing in May of 1988, it was full of bland compromises, but it was nonetheless noteworthy in the face of political forces and represented a net victory for public health over right-wing pressure.

Enlistment of the electronic media in the general educational effort has been even less effective. Despite intensive use of television advertising by other agencies of the U.S. government such as the Department of Defense in their recruiting programs, it has been technically illegal for the U.S. Public Health Service to expend its funds for purchase of prime time. Thus, public service announcements about AIDS have been confined to off-peak hours (usually the small hours of the morning), and even then their use has been dependent on the willingness of networks to donate time. The delicacy of this arrangement has not withstood pressure, for network executives almost uniformly rejected proposed spot features concerning condom efficacy in reducing HIV transmission risk and their acceptance was limited to a few urban areas in which the judgment of local producers and/or owners

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deemed the risk of AIDS worse than the risk of angering viewers. That the AIDS education "spots" commissioned by the U.S. Public Health Service for national airing have barely been used reflects lack of leadership at the highest levels of the federal government. It is of interest as a contrast that when the state of Michigan produced an array of television spots in the supportive atmosphere of a public health department and task force backed by the governor, major network affiliates and radio stations in the state readily introduced them into prime-time slots as a public service.

Some of the rationale offered for federal inaction is that public health lies within the province of local and state governments and that in certain areas, educational initiatives have indeed been more successful at the state and local level. Since the resources available to public health officers vary greatly, access to basic information concerning HIV and AIDS has been unequal among the various states.

Ideally, community-based and target-group-directed facets of education for prevention would serve to supplement and refine general educational offerings and would have somewhat different goals from more widespread initiatives. At the community level, diversity of language, mores, and social circumstance can be accommodated in conveying fundamental information about AIDS.

Finally, the need to teach children and adolescents about this new threat has been generally—albeit unevenly—recognized. Most school curricula are determined in the United States by some combination of state and local authority overseeing scope and content. It is an interesting phenomenon of the epidemic that, of the complex and frequently repressive items of legislative initiative at the state and local level, the most constructive and successful have been mandates for state educational programs to incorporate AIDS information and some version of sex or health education into their school curricula early on. Political arguments have tended to focus on when, not whether, such material should be introduced.

Targeted education programs designed to convey practical messages of prevention through behavior modification have also been successful. Studies of gay communities in San Francisco and New York have documented the efficacy of programs in which safer sex practices have been taught and fundamental messages concerning risk behavior given. Whereas rates of new infection had been as high as 8 percent per year in the recent past, in 1987 they dropped below 1 percent. This drop

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does not mean that the problems of homosexual transmission have been solved, but it is heartening reinforcement that education about risk behavior can be an effective weapon against HIV.

Along the northeast corridor of the United States, former addicts have been mobilized to teach how to sterilize needles with bleach and what the hazards of sharing injection apparatus are. The results of these efforts are more difficult to document, but the steep slope of the curve of increasing HIV prevalence among intravenous drug addicts in the New York–New Jersey area has leveled off in synchrony with such pilot programs.

The messages that emanate from target-group interventions are politically mixed: it is difficult to avoid the conclusion that, if one wishes to communicate, it is best to use the language of one's intended listener; and the results bear that out. However, the wish to use understandable language flies in the face of powerful political forces that consider AIDS to be "God's punishment" for sins that put sufferers at risk. Much more compelling cautions come, too, from the communities in which risk behaviors such as intravenous drug addiction threaten existence itself, for perceptions of the future may be so bleak that needle access means not treatment and health but easy entry to a brief escapist existence. At the least, advocacy of targeted interventions puts political figures into a very dangerous line of fire that is sometimes perceived as lethal for future political aspirations.

Why the United States should have been crippled so uniquely in the prime area of education for prevention of further HIV dissemination is a matter for speculation, but it surely involves issues of provincialism, right-wing moralism, and homophobia.

To be fair, part of the explanation derives from the epidemic being recognized first in the United States, so that the warning later available to other countries was not at hand. That situation could justify the slow start, but the persistent reticence in communication, even about fundamental facts of HIV biology and spread, seems to betray a more profound difficulty of political will. Homophobia clearly lies behind some of the inertia; and denial is another powerful force as the issue of heterosexual spread is admitted reluctantly into the discourse.

The evolving recognition that heterosexual spread sometimes reflects bisexuality spells real trouble, for the latter is a nearly universal feature of human culture and yet is very little discussed or

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dealt with in the preventive approaches thus far devised. The role bisexuality has played in the epidemic to date is difficult to quantify, but it constitutes a critical area of sexual behavior that will broaden the exposure to HIV of women and therefore of children. Black and Hispanic communities, in which declared homosexuality is very uncommon, acknowledge far more than do other communities frequent sexual contact between men who are generally heterosexual in their orientation and behavior. The risk of HIV infection among male prostitutes is high, and their clientele is composed in substantial part of married men whose usual social orientation is "straight."

HIV Testing and Counseling

The U.S. political scene, both state and federal, has been littered with proposals to deploy the antibody test for detection of HIV-infected persons. Mandatory testing of potential donors of blood is wise and has been in place since the spring of 1985. Similar provisions for screening donors of organs, tissues, and cells have evolved as the documentation of risk has added up. The urge to extend that mandate to other groups in the population has proved irresistible to many politicians, despite the nearly unanimous consensus of public health professionals that testing without counseling is of dubious value. In the 1987 legislative year, more than 550 bills concerning AIDS were introduced into U.S. state legislatures, and the great majority involved some permutation of involuntary testing. In 1988 the number grew to over 800.

It is not possible to deal with all the variations on the theme of widespread antibody testing, but several prominent issues surface repeatedly. Should premarital testing for HIV be required, as it was for syphilis generations ago? (More than half the states have discontinued their requirement for syphilis serology because of an unfavorable cost-benefit ratio). Should all pregnant women be screened? All prisoners? All patients admitted to hospitals or all health-care workers? All immigrants or all international travelers? Since the public health impact of such testing (absent counseling and health-care provisions) is negligible, it is compelling to recognize that in both federal and state legislative arenas, these topics have consumed the political energies of the United States out of all proportion to their public health relevance.

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It is also instructive to note at the outset that even the limited programs of voluntary testing and blood-donor screening have overtaxed the supply of personnel who could provide counseling. Since counseling, not testing, is the fundamental mechanism whereby testing can interrupt further HIV spread, any diversion of that activity to groups in which the risk is lower and/or the benefit less clear would intensify the demand for a scarce human resource that is critical to the recommended public health response.

The emphasis on counseling may seem to be overdrawn, but in its absence testing has marginal or even negative value. First, the news that one is seropositive has proved to be a potent depressant; suicide often follows such notification. One goal of counseling is to anticipate and counterbalance this effect. Second, simply telling persons that they are seropositive has little public health value unless they can learn the meaning of that result and be counseled concerning behavior changes needed to reduce their risk of spreading the virus to sexual or drug-using partners. Even worse from a public health point of view, to a person given to risky behavior, a negative test unaccompanied by counseling may seem assurance of invulnerability, with the quixotic result that he or she takes still more risks.

Expecting too much of the HIV test seems to be universal and surely reflects today's tendency to turn to technology for solutions to social problems. Political debates have swirled in countries throughout the world, and the social dangers of thoughtless initiatives such as international traveler screening prompted the World Health Organization's Global Program on AIDS to sponsor a pair of consultations about screening, one for international travelers and the other for the general population. The consultations are worth reading, but their central theme is that testing per se is at best transient in its validity, highly prone to false-positive error when applied to low-incidence populations, and potentially distracting in that diversion of the considerable resources needed saps other more directly useful facets of public health activity. These arguments apply with particular force to the 1987 U.S. policy of immigrant screening, which is a serious misapplication of testing technology, inviting international backlash as well as false confidence.

Premarital screening provides an apt example of diversion of resources. For instance, the state of Illinois began a mandatory program of premarital screening at the beginning of 1988. In the first

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eleven months, only 23 of the 150,000 people tested (or 1 in 6,500) were positive. The cost per person tested ranged from $25 to $125, and Illinois officials estimated that the cost of finding each of the 23 infected people came to $228,000. Meanwhile, the number of couples seeking marriage licenses in the state decreased 25 percent. The combined loss of revenue and low yield led state officials to urge abandonment of the program by the end of its first year.

While premarital testing is a state prerogative, a useful theoretical study by Cleary and colleagues in 1987 shows the likely outcomes of premarital testing for HIV in the United States were it to be mandated nationwide. Using suitably conservative assumptions and data (based on 3,800,000, the number of persons married in the United States in 1982, as a total), they concluded that such an exercise would reveal 1,300 infections in persons who would not have been identified otherwise, would reassure 150 infected persons falsely that they were seronegative, would inaccurately label 350 as infected, and would incur an annual cost of $100,000,000.*

Routine or required screening of pregnant women or of all patients on admission to hospital presents similar cost/benefit concerns as well as raising again the matter of counseling as a central requirement for the usefulness of testing. In the screening of patients, the chief hazards would be false confidence on the part of health-care workers and lost confidentiality and/or quality of care of patients who tested positive.

As for mandated premarital testing, while intrauterine HIV infection of a fetus is a tragedy, the virus has less than a 50 percent chance of transmission when a pregnant woman is infected. Thus, the issue of termination of pregnancy, which is already politically troublesome, is less than clear-cut even on medical grounds. Furthermore, the distribution of HIV infection among women is radically different in various regions and populations: in fact, nearly 80 percent of HIV-infected women in the United States belong to either black or Hispanic ethnic minorities, and while heterosexual and drug-associated transmission of HIV is growing in frequency along the East Coast, the West Coast epidemic has remained very dominantly a male phenomenon to date. Thus, the resources that might be

*See Paul D. Cleary et al., "Compulsory Premarital Screening for the Human Immunodeficiency Virus: Technical and Public Health Considerations," *Journal of the American Medical Association* 258 (13) (2 October 1987):1757–62.

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diverted by generally mandated prenatal HIV screening would be wasted in large parts of the country. Some countries in Africa have found HIV antibodies in more than 10 percent of pregnant women tested, and where HIV prevalence supports such initiatives, it makes good sense for physicians to advise women to be tested. However, it is generally unlikely that mandatory testing can achieve as much as could programs in which the consent of the woman was obtained prior to testing.

The same kinds of analyses can be applied to other testing and screening proposals. In general, it is helpful, in assessing the potential benefit of such initiatives, to identify clearly what use will be made of the results. For instance, screening of prisoners begs the problematic question of prison crowding and raises difficult issues of confidentiality and equal treatment under the law. Prisoners have been the target of many involuntary testing proposals because of the perception that they are likely to be infected, the fact that drug use is a frequent concomitant of crime, and the unreasonable fear of their guardians that infection spreads through casual contact. Some proponents have justified their stand on grounds that homosexual rape is common in prisons and that therefore other prisoners should be protected from HIV risk by incarcerating infected men separately.

A common feature of most prisons *is* overcrowding, and it is difficult to understand how occasional seropositive persons could be imprisoned separately without seriously impinging on overall space constraints as well as on the confidentiality of the persons thus isolated. In point of fact, seropositivity among prisoners has turned out to be considerably less common than was first suspected, spread within prisons has not been documented, and some prison officials have noted informally that the problem of homosexual rape has actually diminished because of prisoners' fears that some among them might be infected. In summary, while prisoner screening is regularly discussed in the context of public health programs to contain HIV, its actual usefulness is problematic and dependent on so many local variables that it is best assessed in terms of specific state or community priorities, and epidemiologic realities and resources.

In prostitute testing, again, it is important to know in advance what use can be made of test results. Numerous jurisdictions have found, to their embarrassment, that recidivism among persons engaged in commercial sex is almost certain to occur unless they undertake job

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retraining and that prison crowding makes sustained incarceration an unreasonable solution. Furthermore, in the United States at least one-third of female prostitution is directly related to drug addiction, for which treatment resources are in desperately short supply. In both the general case of prisoners and the specific matter of prostitutes, however, the politics are lopsided, for there is little or no advocacy that would encourage constructive resolution, and the political imperative to appear "tough" tends to overwhelm the dialogue.

The usefulness of testing, more than perhaps any other aspect of HIV prevention, rests on the tone and perceived intent of public programs. The foregoing examples demonstrate how illusory benefits derived from mandated programs are. An additional comment is required about optimizing the use of the HIV test, for even voluntary testing can be threatened by the social atmosphere. Voluntary counseling could be an exceptionally useful cornerstone of public health policy for persons at risk where their immediate test results are positive or negative: those who are infected need to learn to avoid activities that might transmit the virus further, and—at least as important—those who are not yet infected need to recognize their peril and not engage in further risk behavior. The role of testing in that context is to reinforce the messages of counseling. (In fact, some data suggest that, so far as prevention is concerned, the test result itself plays little part when individual education is effective.) Many physicians argue that one benefits medically from knowing that one is seropositive, beyond the obvious ability to protect one's loved ones.

Thus, several lines of reasoning argue for accessible voluntary counseling and testing resources as a central facet of AIDS prevention. However, it is evident to public health professionals that the usefulness of such programs is entirely dependent on the credibility of provisions made for anonymity or confidentiality of test results and that the demonstrable and perceived threats of discrimination to seropositive persons serve as powerful disincentives for persons at risk of AIDS.

That point emerged as such a dominant consideration during hearings of the U.S. Presidential Commission on the Human Immunodeficiency Virus Epidemic that its chairman, James Watkins, identified setting up antidiscrimination assurances through legislation or presidential directive as the most urgent requirement for making progress in prevention. (That that intensity of concern failed to

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inspire action on the part of the Reagan administration, however, shows how divisive the issues surrounding AIDS have been.)

Perhaps the most heated political debates thus far have swirled around confidentiality and anonymity. Several states have adopted requirements that seropositive persons be reported to public health authorities but that confidentiality be guaranteed. Even so, it is alleged that unease about the reliability of such assurances has a chilling effect on participation.

Concerns about confidentiality have become much more focused recently, as corollary issues of contact tracing and/or mandatory partner notification have entered the discussion. The politics of these provisions are exceedingly complex, for in some states physicians lack the legal power to report HIV infection without their patients' consent, while in other jurisdictions failure to report may be punishable. The legal groundwork for such regulations is not well defined. Fundamental matters of privacy and patient-physician relationships are at issue.

From the public health point of view, there are battles to be won but wars to be lost by coercive notification legislation. Individual cases clearly warrant deep concern when HIV-infected persons adamantly refuse to warn their sexual partners of risk. Then legal authority to supersede willful nondisclosure seems desirable. On the other hand, with deeply closeted behavior such as bisexuality growing in importance as a vehicle of epidemic spread, disclosure on the part of a physician though not required would certainly ensure that no further persons at covert risk of AIDS would knowingly enter his or her care.

WHO consultants recently concluded that health authorities should use caution in requiring partner notification, for programs to notify sexual partners might divert resources that could be better used for other purposes, and that some members of groups at high risk of developing AIDS might avoid being tested or seeing physicians at all if they feared release of information about their infection to their partners. The tone and style of public health activities in this epidemic is nowhere more important than in this difficult area. Surely categorical political stances are too blunt and indiscriminate for such delicate issues, and yet the matter of partner notification has been one of the

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critical elements in the debate over counseling and testing legislation in the U.S. Congress.

Preventing Spread through Drugs

The need to deal with intravenous drug use in the United States as an open pipeline to broadened spread of HIV is urgent. The battle lines were drawn in a declared "war on drugs" before HIV was recognized to have infiltrated the scene, but it would take a degree of optimism even to call it a standoff. The war was perceived to involve only legal combatants, and essentially no public health or medical interests were acknowledged. As in most wars, issues were etched in sharp relief, and no softening shadows blurred the categorical choices. The wartime call to arms was "Just say no, or else!"

Thus far, the AIDS epidemic has had little effect on that array of forces, but it has underscored the omission of mercy from drug strategies: it is an allegedly moral conflict, and yet no accommodation has been made for the "prisoners of war." Few claims are made for truly satisfactory approaches to cocaine abuse, and efficacy of drug treatment for opium addiction is a topic of some debate. For heroin addicts, methadone maintenance and/or detoxification offers some possibility of escape from the nightmare of addiction, but the inadequacy of treatment facilities in the United States is startling. Waiting lists in most large urban areas are several months long. Nonetheless, peripheral efforts at drug control have made possession as well as purchase of injection apparatus a legal offense. Needle sharing among intravenous drug users has taken on the significance of blood brotherhood, and by this route HIV has made its most deadly inroad into the future of thousands of young adults in both the United States and Europe. In Europe needle-exchange programs have been adopted in many areas, and while results are uncertain regarding curtailment of HIV spread, there has been no suggestion that drug use has increased as a result. In the United States only a few small experiments to assess needle exchange have been started in urban areas. The debate is intense, substantial opposition coming from involved minority communities.

Were drug-treatment options available to those who wanted them in order to attempt escape from opiate addiction, the needle option might be too problematic to pursue. Drug treatment on demand was the first and most urgent need identified by Admiral Watkins as the

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presidential commission did its work, and it remains a compelling agenda item from the point of view of public health officials. Needle-exchange programs, on the other hand, are clearly not lasting solutions to HIV and drug use; but if the sole option for persons driven by addiction is forced sharing of injection gear in populations where seropositivity for HIV exceeds 50 percent (as it does in the New York–New Jersey area), then controlled exchange of clean for dirty needles seems a logical and important stop-gap measure.

Again, it is distressing to note the paralyzing passion that has characterized the political debates concerning these points. More than 200,000 persons are estimated to be addicted to intravenous heroin in New York alone, and it has fewer than 40,000 treatment "slots." Nevertheless, the commissioners of health for New York City and New York State take opposite positions on the needle issue, and even the effort to institute a trial program of needle exchange on a small scale in New York City has fanned political flames. The stalemate has disastrous implications, for more than half the AIDS cases in New York City acquired HIV from the use of drugs, and the projected numbers threaten to overwhelm systems of health care while the source of further infection continues unimpeded.

Sadly, some drug users have perceived heroin, rather than injection, to be the risky component of their behavior—evidence of the failure to educate clearly about risks. This perception has added momentum to the trend to use cocaine rather than opiates, with two dire consequences for the AIDS epidemic. First, not only does injection of cocaine beg "the needle question," but intravenous cocaine is a much more demanding master than heroin. Cocaine wears off in a matter of minutes instead of hours and drives users to almost frenzied injections, which eliminate all likelihood of pausing to clean injection apparatus. Alternatively, "crack" cocaine is frighteningly addictive from the very outset of its use, and sex becomes a ready currency in exchange for drugs.

Both of these forces are evident in the grim contours of the New York epidemic among adolescents and young adults. In the disadvantaged cultures where such outlets from hopelessness prevail, it is not surprising that public health workers and politicians react with horror to proposals that seem to deal gently with such malignant problems as those drug use poses. It takes considerable faith to counteract the despair that pervades these populations and to perse-

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vere with efforts to control HIV. In the curtailment of drug-associated spread, however, lies much of the hope for containing the AIDS epidemic a decade from now.

ISSUES IN PATTERN II AND III COUNTRIES

The themes discussed thus far have been particularly prominent in industrialized countries conforming to Pattern I. Aside from the spread of HIV primarily through homosexual behavior and drug use, these countries have highly developed surveillance systems, which facilitated nearly instant recognition of AIDS. In retrospect, of course, their early warning was illusory since the virus has such a long incubation interval; but at least public health activities could be mobilized at the first recognizable sign of infection caused by the human immunodeficiency virus.

Pattern II countries have less advanced systems of health care. There surveillance is not as well planned, and the general background of febrile and debilitating disease makes recognition of AIDS more problematic. Homosexuality as such has been far less overt in the cultures of these nations, although bisexuality is tacitly accepted and may be widespread. Thus, the Caribbean nations, which experienced some of the earliest outbreaks of AIDS, often rejected communications from the United States because of the prevalence of homosexuality and drug use there, and African countries took deep offense at suggestions that the HIV virus might have originated on their own continent. These kinds of forces made it nearly impossible for political leaders to acknowledge publicly that their countries were involved.

Such denial persists in some regions to the present, despite occasional focal surveillance studies suggesting that HIV infection may be appallingly widespread. A case in point is Zambia, where official denial of AIDS as a problem persisted until the fall of 1987, when the son of President Kaunda died of AIDS and moved the father to declare an end to the silence. One of the features of the African epidemic has been the disproportionate involvement of young men from the advantaged and educated elites, to whom the mantle of leadership was to have been passed.

As open acknowledgement of the AIDS epidemic widens in Africa, the scope of the disaster becomes evident. Studies of blood donors in Kenya and Tanzania reveal as many as 20 percent to be seropositive.

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Surveys of pregnant women in central and eastern Africa commonly show 3 to 5 percent to be infected and much greater proportions in certain urban areas. HIV-related illness accounts for 25 percent of the hospitalization in regions strapped to provide health care of any sort. The blood crisis alone is startling in its scope, for even preliminary HIV screening represents an overwhelming expense. The cost of a single blood test may exceed the annual per capita health-care expenditure.

The political dynamics of such a catastrophe are beyond the scope of this discussion. Suffice it to say that thoughtful observers consider destabilization a legitimate concern in some countries because of the combined impact of demographic shifts and the vacuum in leadership.

The competition between HIV-related activities and other facets of public health in Pattern II countries is particularly cruel. Needles for medical injections are scarce and often reused; and for both realistic and irrational reasons, crucial initiatives such as the Expanded Program on Immunization of the World Health Organization are threatened by fear of AIDS. (There is no dispute among public health professionals, however, that the risk-benefit ratio weighs strongly in the direction of continued immunization.) Breast feeding, too, has become an issue, for HIV can be shown to exist in breast milk and on rare occasion has been conveyed by that route to the suckling infant; yet in large areas where AIDS is a theoretical risk, malnutrition and starvation are real and will present dangers if breast feeding is abandoned.

Choices about these stark issues make the tasks of public health workers and politicians all the more difficult, but it is noteworthy that even countries deeply and demonstrably afflicted by the HIV incursion have begun to commit themselves to devising culturally relevant education for prevention.

Pattern III countries may face the greatest political challenge of all, for there politicians are least prepared to anticipate the gravity of distant threats. Each nation has a strong urge to pretend that its lack of involvement with HIV can be sustained and that harshly repressive measures will serve as an adequate wall to circumscribe their populations. The intimate behavior that spreads HIV defies such legalistic strategies, and realistic assessment of virus-containment

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measures argues for preservation of human rights as a necessary central ingredient for effective public health policies.

THE MORAL FORCE OF WHO

When one reflects on the difficulties encountered by policymakers in the United States in the face of a massive epidemic problem, the need for ostensibly uninvolved countries and governments to initiate discussion about delicate topics of sexual behavior and to launch public education campaigns is compelling but awkward in the extreme. In this light it is remarkable that most of the nations of the world have embraced the aims and objectives of the Global Program on AIDS of the World Health Organization. As a minimum they have established national HIV committees, launched public HIV and AIDS education campaigns, and identified national needs that can be met in collaboration with WHO and, through them, with donor organizations.

The success of the Global Program on AIDS serves as a counterweight to the gloom of national deficiencies in public health responses to AIDS. The international activities alluded to have been augmented by several consultations dealing with troublesome topics of general concern about HIV, for which global consensus seemed desirable. There have been repeated discussions of blood and blood products, HIV research, and vaccine development and testing. Consultations have been held concerning international traveler screening, screening as a general feature of HIV control programs, neuropsychiatric aspects of HIV infection, and policies concerning partner notification. These meetings have produced consensus documents that have proved to be of considerable help to member states. While WHO is a supranational entity and therefore technically lacking in political power, its persuasive moral authority carries considerable weight and has been well mobilized under the thoughtful leadership of Dr. Jonathan Mann, from the Global Program on AIDS; of Dr. Halfdan Mahler, director general from 1973 to 1988; and of Dr. Hiroshi Nakajima, the newly elected director general.

The moral force of WHO may be a suitable topic with which to conclude an analysis of public health, politics, and AIDS. The unique challenges of the epidemic lie in mobilizing detailed and reassuring information about restricted modes of HIV transmission; in creating and maintaining a tone and style of public health endeavor

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in which frightened persons at risk can come forward to learn how to modify their behavior; and most profoundly, in responding to a pandemic without panic and taking care to maximize preservation of human rights.

Preventable destruction of human life and talent is the price of failure to contain HIV; unnecessary infringement of human dignity and freedom is the price of giving way to a primitive lack of reason and fear. The political challenge to preserve the health of the public while avoiding these tragic excesses will dominate the public health agenda for a decade or more to come.

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Harvey M. Sapolsky

AIDS, Blood Banking, and the Bonds of Community

THE RELATIVELY SMALL THREAT of contracting AIDS through blood transfusions in the United States has led to significant improvements in the overall quality of American blood services, nearly all of which could have been achieved without the existence of this new health menace. Nonautologous exposures to blood are always hazardous. Transfusions save lives, but they can also transmit life-threatening diseases, AIDS being only one of them and not the most prevalent. The danger extends beyond transfusion recipients. Health-care professionals are placed at risk through accidental blood spills and needle sticks. However, as blood-banking services have expanded, the handling and use of blood have become incautious. Organizational convenience rather than safety has often guided behavior. But fear of AIDS is so great that attention has galvanized efforts to reduce risk, forcing long-needed changes in medical practice.

The number of transfusions, previously increasing in the United States, has declined, for greater care is being taken in prescribing blood. New tests for rare as well as common hazards are being applied to blood. Autologous donations, the safest kind, are up sharply. Research on blood substitutes has expanded. The handling of blood is carefully audited. Health-care professionals rightly worry about their exposure to blood, for accidental blood spills and needle

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sticks put them at risk of acquiring the HIV virus. While organizational convenience rather than safety had begun to guide their behavior as blood-bank services expanded, now they take the time to put on gloves and masks whenever they come in contact with blood.[1]

Taking these and other precautions has reduced the risk of transmitting AIDS but not eliminated it. The tests are not perfect; medical mistakes and accidents still happen. The risk of contracting AIDS through transfusion may grow if the disease spreads from the current high-risk groups to the general population and further contaminates the pool of available blood donors.

Irrespective of the actual risk, the search for increased safety caused by the fear of AIDS alone may be sufficient to alter drastically the structure of blood banking. In the United States, as nearly everywhere else, the provision of blood for transfusions is largely a community responsibility. Without knowing who the recipients are and without direct monetary reward, those who can, donate blood for those in need. But several of the remaining ways in which the safety of transfusions can be enhanced require the breaking of this bond of community, improving chances for some recipients while perhaps harming those of others. Individual gain at the expense of the community is not uncommon in society. In this instance, however, the gains and losses are measured in lives.

TO WORRY ABOUT TRANSFUSION RISK OR NOT

The first suspicion in the United States that AIDS has a link with transfusion developed in mid-1982. By then three cases had been identified among hemophiliacs, who because of their disease, are heavily dependent on the use of blood products. About that time an infant in San Francisco was diagnosed as having AIDS, the probable cause being a transfusion received at birth. Several possible transfusion-related cases were also under investigation. Given that the disease was concentrated among male homosexuals and intravenous drug users, some federal officials saw in AIDS a pattern similar to that observed in hepatitis B, a blood-transmitted disease that is endemic in the same populations and that is a serious hazard of transfusions. Immediately, the officials began to express their fear to representatives of the several blood-banking organizations, that the blood supply was being contaminated. These discussions culminated

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in a meeting in early January 1983 at which proposals were presented to screen out members of high-risk groups from the donor pool. The AIDS antibody test not then being available meant that members of high-risk groups would have to identify themselves through questionnaires and/or interviews.[2]

The response to these screening proposals divided along the lines of blood banking in the United States—into the two sectors of plasma and whole-blood collection. The plasma sector, which is controlled by a handful of large pharmaceutical firms and which pays its blood donors, indicated its intention to adopt screening protocols to bar collections of plasma from high-risk groups.[3] One of the main uses of plasma is for the production of fractions that are vital to the treatment of hemophilia. The American Hemophilia Association, which was also represented at the meeting, had already declared its desire that protective measures be implemented right away—an appropriate stand because hemophilia victims were soon devastated by the AIDS virus. Clotting factors for hemophiliacs are made from pooled plasma lots composed of as many as 5,000 donations and can be contaminated by a single AIDS virus carrier. Nearly half the 15,000 hemophiliacs in the United States are now infected. Among the victims of the most severe form of hemophilia, who necessarily have the greatest exposure to the clotting factor, the infection rate is estimated to be 70 to 90 percent.[4] The effects of the contamination are worldwide because the United States has been the major international supplier of plasma products.[5] With the recognition that AIDS is caused by a virus, a heat treatment that kills the virus in the processing of plasma fractions was developed.[6] It made protecting the hemophiliac population from further risk possible.

The other blood-banking sector collects and processes whole-blood donations for transfusions and is almost entirely composed of nonprofit regional blood centers and local hospital blood banks that do not pay donors. Nationally, this sector is represented by three organizations with somewhat overlapping memberships: the American Red Cross (ARC), the American Association of Blood Banks (AABB), and the Council of Community Blood Centers (CCBC).[7] Arguing that evidence was not sufficient to exclude gay men from the donor lists or to implement the use of surrogate tests like that for hepatitis B core antigen, which had also been proposed, their

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spokesmen opposed the screening proposal at the January 1983 meeting.

The words one of them used are often cited to show the concern expressed about disrupting established routines: "We are contemplating all these wide-ranging measures because one baby got AIDS after a transfusion from a person who later came down with AIDS, and there may be a few other cases."[8] The opposition of the whole-blood collectors delayed government action intended to reduce the risk of AIDS transmission through transfusions. It was not until March 1983 that the Centers for Disease Control made public the recommendations for widespread screening.[9] This public announcement forced the banks to begin excluding high-risk donors.

Structural differences help explain the inconsistent responses to AIDS within blood banking. The whole-blood sector relies on voluntary donors. Women and minorities give less frequently than do young white males. In several cities the gay community has been a readily accessible, often organized, population of young white males to solicit for donations. Through repeated campaigns, the blood banks have built good relations with the gay community and found it to be a convenient source of donations. Many gays used to believe that the call for screening was scapegoating and saw in it a threat to their recently won gains in civil liberty.[10] Sensitive to the concerns of the gay community, some influential blood bankers were reluctant to force the exclusion of gays and doubted the effectiveness of direct questioning of donors to achieve that exclusion.

In contrast, plasma collectors have paid their donors. If one group of donors has been excluded, another has been quickly found to maintain the supply. The plasma collectors' relationship with donors has been solely financial and has not been an attempt to build long-term trust or mutual support.

The plasma sector has also been highly competitive, producing products that are interchangeable among manufacturers and marketable internationally. The buyers of these products are knowledgeable about differences in quality, some being government medical agencies and others individuals who must be in constant contact with medical specialists because of their illness. The firm with a demonstrably safer product would rapidly gain business.[11] Once donor screening was suggested as a possibility for reducing the risk of transmitting AIDS,

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plasma collectors had no choice but to adopt it out of fear that at least one of them would start screening and capture the market.

The whole-blood sector lacks many of these characteristics. It is dominated by nonprofit blood-collecting agencies that are local monopolists, supplying all or nearly all the blood transfused within a given region. Blood quality in transfusions is more the responsibility of the supplier than of the purchasing hospitals. Nationally, the Red Cross, the AABB, and the CCBC coordinate policies, effectively cartelizing the whole-blood sector by refraining from competing with one another. A hospital seeking an alternative to its local blood center has difficulty obtaining services from an extraregional supplier. Although hospitals can be licensed to draw their own supplies, for most hospitals economic and professional obstacles discourage the use of this option.

The structure of blood banking in the United States changed in the early 1970s when the federal government responded to the urging of the nonprofit collectors to adopt policies favoring voluntary blood donations in collections for transfusions.[12] Richard Titmuss, the English sociologist, had just published a widely praised comparative analysis of the American and British blood-banking systems that helped focus public attention on the risks of transfusion-related hepatitis.[13] In a devastating critique of the American system, Titmuss argued that payment for donations significantly increased the hepatitis hazard for transfusion recipients. In Britain, where the most a donor could get for his donation was a cup of tea or a glass of stout, hepatitis was not a problem, but in the United States, where substantial payment was permitted, the gift of life was often something else, he claimed. The nonprofit collectors, under pressure to improve the safety of transfusions, promoted this view, inaccurate though it was, and sought the elimination of commercial collectors and payment for donors from the whole-blood sector.

The critique was quite misleading because transfusion hepatitis rates do not correlate well with donor payment. Sweden pays all its donors but has a low hepatitis rate. In the 1960s Japan switched from a largely paid donor system to an exclusively voluntary one without greatly altering its high hepatitis rate. The low rate that Titmuss observed in Britain probably had more to do with British blood being transfused there than the fact that British donors are not paid. Incredibly, Titmuss failed to mention the extra precautions that the

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British transfusion service was taking to keep the hepatitis rate down. It has avoided collections in areas that have large concentrations of immigrants to Britain from Third World countries where hepatitis is endemic. The service has also labeled blood donations by race and has not transfused the blood donated by Pakistani, African, and other immigrants. In addition, Titmuss ignored the fact that some of the leading medical institutions in the United States, the Mayo Clinic and the Massachusetts General Hospital among them, have paid donors but have had low hepatitis transfusion rates due to careful donor-screening practices.[14]

Ironically, paid donations were not a major factor in American blood collections in the early 1970s, because the commercial collectors, which did most of the paying, had already shifted their attention to the plasma market, which was rapidly growing because of the discovery of important plasma products. Plasma donations are more demanding in terms of time for donors and usually require monetary compensation. Federal policies encouraging voluntary donations for transfusion merely assured the nonprofits that competition from commercial collectors would remain limited. The nonprofits attempted to consolidate their position further through a cooperative program of regionalization that certified dominant collectors as monopoly suppliers in designated areas.[15]

Not surprisingly, these actions had little effect on the national hepatitis rate. Like AIDS, hepatitis is a complex scientific problem that has eluded quick solution.[16] Research on control techniques continued during the 1970s, but the nonprofits devoted much energy to reducing their responsibility for the continuing presence of hepatitis in the blood supply. They persuaded the federal government and some state legislatures to require the labeling of blood by donor source, either paid or volunteer, with the implication that the transfusion of paid donor blood holds a special legal liability for the transfusing agent. At the same time, the nonprofits obtained legislation in nearly all states designating blood a service rather than a product, thus exempting themselves from liability other than for negligence when hepatitis or any other disease is transmitted via transfusion. Since they set their own practice standards through professional organizations with relatively little government supervision, however, negligence itself becomes difficult to prove.[17]

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The nonprofit blood banks hold a unique position in American medicine. They are protected from commercial competition, exempt from most consumer suits, and free to divide geographic markets among themselves. As economists remind us, monopolists prefer the quiet life free of public scrutiny. When the AIDS crisis appeared, the blood bankers' inclination was essentially to deny that it was a major threat to blood safety. Special donor-screening procedures were ineffective and disruptive in their view. Attempts to implement them would only call attention to the disease's link to transfusions, consequently frightening both blood donors and recipients. And when the AIDS antibody test was developed in 1985, the blood bankers proclaimed it entirely sufficient to protect the blood supply. There was no longer a need to worry about getting AIDS through transfusions, they implied. Unlike many in the society who have sought to exploit public fear about AIDS, blood bankers have continually offered reassurance that all is safe despite AIDS.[18]

RISKS REMAIN

About 3 percent of the AIDS cases recorded in the United States are attributed to the therapeutic exchange of blood. The AIDS toll is certain to grow, but the transfusion-related share of that toll is not. The AIDS antibody test provides an important, although imperfect, defense against the spread of the disease through blood services. So do improvements in medical practice.

The number of transfusions given annually in the United States, which approached the 4 million mark in the early 1980s after years of steady growth, is now declining. Precise figures are not available because we have no national blood data system, but estimates are that there has been a 6 to a 10 percent decrease.[19] The tendency in at least the major medical centers is to avoid transfusion unless defined need criteria are met. No longer is it common for a physician to order a unit of blood to put the blush back into the cheeks of a patient about to be discharged from a hospital. And when considering surgery, physicians and patients think harder than they once did about the risks of transfusion.

A rarity prior to AIDS, autologous transfusion, achieved through either the predeposit of blood from the patient or its intraoperative salvage, account for as much as 2 percent of blood usage and is

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growing in popularity.[20] Blood banks have not encouraged the practice, despite the safety advantages offered patients who can anticipate their need for blood and who are healthy enough to provide the donation. Autologous collections cause inventory complications for blood banks and contradict their donor-recruitment message that blood is a community responsibility. But the fear of AIDS among patients and among surgeons as well has left the banks with little choice but to advocate the maximum possible use of autologous donations.

Ultimately, it is the AIDS test that guards transfusion. Not all uses of blood can be avoided, nor can all recipients provide for themselves. When someone else's blood is to be transfused, safety depends on the effectiveness of the screen. In the case of testing for AIDS, as in the case of many other diseases, the screen is less than perfect. Some infected units will get through.[21]

The most commonly used screening test for AIDS is the enzyme-linked immunosorbent assay (ELISA). Blood-bank procedures require each donated unit to be screened by the ELISA test immediately after collection. Positive units are then rescreened twice. If either or both of the rescreening tests are also positive, the unit is considered unusable and not transfused. (Many but not all blood centers discard initially reactive units even though this status is not predictive of the disease.) A confirming test, usually the Western blot, is performed before the donor is notified of a positive status. Most ELISA positives turn out to be false positives.[22] The ELISA screen is purposely set low so as to eliminate as many dangerous units as possible. The purpose of this process, however, is that some blood pass the screen so that there will be blood for transfusions. A perfect screen for a low-incidence population like blood donors would under current conditions mean substantially reduced blood availability. As it is, nearly 1 percent of donated blood is discarded on the chance that it might be HIV infected.[23]

For the potential recipient the issue is not how many units are discarded but how many infected units are passed into inventory and transfused. Technician error, faulty test batches, and mishandled units ensure that some HIV-infected units get through. More significantly, the AIDS screen as an antibody test has inherent limitations. One problem is that infected individuals do not immediately produce antibodies to HIV. Several weeks pass before antibodies begin

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appearing in the blood of a virus carrier. Those in the terminal stage of the disease may also be antibody free. There are also reports of a few victims who do not produce detectable antibodies in the middle stages of the disease.[24] Absent the use of a test for the HIV viral antigen, which is under consideration, there will always be some false negatives as long as infected individuals donate blood. And some potentially infected individuals will continue to donate if only because blood banks unintentionally provide a convenient and confidential way to discover one's antibody status. The question, then, becomes how many infected units pass into the blood supply and cause AIDS.

Several factors complicate the calculation of the blood-related AIDS transmission rate. Not all collected blood is transfused; upwards of 10 percent of the units are discarded due to outdating. Transfusion recipients are often severely ill; as many as half die immediately or shortly after transfusion because of their underlying conditions. Not every infection necessarily produces a defined AIDS case; AIDS-related complex, milder infirmity, or no disease may result. And the incubation period for AIDS may be longer than ten years, so not all cases contracted since the antibody screen was implemented have yet been identified.

Blood bankers, concerned about the impact that fear of AIDS has on public confidence in the safety of the blood supply, were at first overenthusiastic about the effectiveness of the antibody test and proclaimed its arrival as ensuring the total elimination of HIV infection risk from blood use.[25] Since then they have had to acknowledge the test's inherent limitations and to revise frequently their estimates of the continuing AIDS risk in transfusions. At first the rate was cited as 1 in a million. Then it was 1 in 300,000. Still later it was 1 in 100,000.[26] Currently it is listed as between 1 in 10,000 and 1 in 100,000, although some researchers claim it is as high as 1 in 5,000.[27] Given the approximately 3.5 million annual new transfusions, that means there are betweem 35 and 700 new cases of AIDS being transmitted through the blood supply each year.

AIDS, of course, as I have said, is not the only hazard of transfusion. Several thousand hepatitis cases, most of the elusive non-A, non-B type, are transmitted each year. Many of them result in death. HIV-2, a virus related to the AIDS agent, has been detected in blood, although not yet in great frequency. The adult T-cell leukemia

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lymphoma virus, HTLV-1, has also been found in blood and has an unknown transmission rate. Screening tests for these viruses are in development, but their efficaciousness has not been determined.[28] Not surprisingly, there is still much public fear about the safety of the blood supply, a fear that affects potential donors even though these tranfusion dangers do not threaten them directly.[29] Donations are down by about 6 percent, and a supply crisis has been averted in some regions only because use has also declined.

Science can make transfusions safer. Better tests and the development of vaccines will help, but the real gains will come from blood substitutes, artificially produced substances that can duplicate the life-sustaining traits of blood components. Much work along these lines is under way, enhanced by the progress being made in biotechnology. Advances there may eventually alter the structure of blood banking and eliminate the need for recruiting and screening blood donors. Given their emphasis on research, Genentech or some other biotechnology firm is more likely to be the supplier of the substitutes than is the Red Cross and the other traditional blood collectors.

SEEKING SAFETY

Even without a breakthrough in synthetic blood research, the structure of blood banking seems certain to change. The fear of AIDS, disproportional though it may be to the actual risk, is sufficient among transfusion recipients and medical staffs to force a continuing search for alternatives to the random draw from the community blood-donor pool. Autologous donations, however, are likely to satisfy no more than 10 percent of the demand for blood because of the unpredictability of need and the frailty of many recipients. The search, then, will be for safer homologous sources. At least three exist, each of which threatens blood banking as it is currently structured.

One safer source is directed donations, the provision by donors of blood to designated recipients, usually friends or relatives who solicit their contributions. Blood bankers have generally opposed this form of donation, as it undermines the basic ideology of the blood system—that blood banks should serve the community rather than individuals and operate like community charities rather than banks with individual accounts. To support their great reluctance to estab-

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lish directed donation programs, blood bankers argue that directed donations are less safe than those of anonymous donors because friends and relatives are likely to conceal high-risk behavior from one another and yet feel compelled to give when asked.[30]

This claim lacks significant empirical support, however.[31] Donors already give under duress amidst friends, if not relatives, in blood drives conducted at work or in clubs and civic groups, where the incentive to conceal risky behavior would be the same as in directed donations. Blood taken through directed donations is screened for HIV, as is all blood. Donors could be provided with ways to ensure that the discovery of dangerous units would not be revealed to intended recipients. More important, as demonstrated in insurance and other industries, individuals and groups often have much to gain by withdrawing from community pools to provide their own protection. This idea should be especially true for achieving isolation from a disease that is focused in distinct groups separated from the rest of the population.[32]

A second alternative is to obtain blood for transfusions from locations that show a very low incidence of AIDS. This already occurs to some extent in the United States because high-donating rural areas subsidize low-donating urban areas in most regions. It is also the unintended by-product of a little-publicized program that imports red blood cells from Switzerland and Germany to New York City, where a chronic blood shortage exists due to inadequate donor recruitment. The Swiss and German Red Cross organizations overbleed their populations to obtain sufficient supplies of plasma for domestic processing. A surplus of several hundred thousand red-cell units is the result. Deftly avoiding the embarrassment that a transfer of cash would involve, they ship the surplus to the New York Blood Center in exchange for blood-processing equipment.[33] Extension of such programs would increase the safety of the blood supply in many American cities but would require recognition that the concept of community responsibility for blood is inadequate or at least requires substantial expansion.

A third option is to pay donors. That is likely to be considered in order to reduce the risk of AIDS transmission in transfusion. The use of direct financial incentives would, of course, reverse federal policies favoring voluntary, that is, noncash, donations, which were established in the 1970s and strongly supported by the nonprofit collec-

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tors. But, as previously mentioned, several of the nation's leading medical institutions once used cash payments to create panels of frequently tested and monitored blood donors to protect against transfusion hepatitis. Today the same procedures could be used to recruit more women, middle-aged people, or other donors who are less likely to harbor HIV or to engage in high-risk behavior.

Although paying blood donors is anathema to nonprofit collectors, they ignore the fact that some voluntary donors already receive substantial cash-equivalent rewards in the form of extra vacation days and time off from work and that blood banks sell blood and other products to hospitals for cash.

Confusing their arguments against payments, directed donations, and increased imports is the blood bankers' concern about the future of blood banking. Each of the reform proposals holds potential for increased competition from hospitals and commercial blood collectors, which are likely to be responsive to the real or imagined fears of transfusion recipients and medical staffs about the safety of blood. But the more compelling public policy must be the effect that reducing the risk of transfusion will have on those who cannot take advantage of the protections made possible by implementing the proposals. They will have to rely on the community supply of blood.

Titmuss claimed that blood-banking systems are symbolic of the relationships favored in a society. Voluntary systems, he believed, encourage altruism and strengthen the bonds of community, based as they are on the giving from one stranger to save another. Payment systems, he thought, are destructive of community because they create a market in the gift of life. Titmuss did not address the subject of directed donations, but he would no doubt view them as divisive and dangerous, replacing trust among strangers with tribal and family selfishness.

Disease can spread by either altruistic or selfish acts. Not every carrier is aware of his exposure to the virus. Tests provide no guarantee that the uncompensated gift from a stranger is safer than the compensated gift from a stranger. Depending on the pool's composition, the random draw from the community pool can be quite hazardous. Titmuss was mistaken in believing that voluntary donations would eliminate the hepatitis problem. We have no assurance that voluntary blood donations will protect absolutely against AIDS.

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Frightened people will seek to protect themselves. Better public understanding of AIDS will surely reduce fears, but it will not eliminate them. Small as well as large risks encourage avoidance. Physicians, entrepreneurs, and policy analysts are certain to inform us how to avoid risks. Neither the fear nor the risk of transfusion-transmitted AIDS will disappear.

Some cannot fend for themselves when fending is required. The elderly, the poor, and the friendless are most vulnerable in systems that permit payment and directed donations. But donor payments may actually decrease blood-collection costs by reducing recruitment expenditures and blood wastage. Much, although not all, blood use is financed through private insurance and government benefit programs. Increased costs, if there are any, can be absorbed in adjusted reimbursement levels or charity drives. More difficult is the identification of directed donors for those in society who are alone or in high-risk groups if this blood-collection method becomes common. Churches, fraternal orders, clubs, and other voluntary organizations may be willing to provide donors for those in need. It is not clear that altruism disappears when alternative donation systems exist. Those who donate for friends and relatives may be quite ready to step forward for others as well.

The more people withdraw from the community pool by making private arrangements to protect themselves, the more likely it is that the shrinking pool will become increasingly disadvantageous for those who must continue to use it. This is the result in too many institutions, urban public schools being the most dramatic example. A cartel of nonprofit organizations is not sufficient to manage this problem. Such a group tends to deny the risks and fears that drive people from the community-based arrangement. Blood banking must become more responsive to the public's concerns if it is to retain broad support.

One possibility would be to remove the exemption from strict liability standards that blood banks have obtained in most jurisdictions. The purveyors of nearly all other products in the United States are held liable for faults that cause illness or death whether or not there have been negligent acts in product preparation or distribution. With the burden of liability shifted back to the blood banks, they would soon adopt one or more of the methods previously described

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to reduce the hazards of tranfusion. Protections that are certain to be available for some could be made available to all.

Another possibility would be for the federal government to encourage interregional and international transfers of blood. In a focused epidemic, some areas suffer more than others. The goal would be to even the risks of transfusion transmissions among locations. Surgical candidates in New York, Newark, and San Francisco need not suffer greater risk of contracting AIDS simply because New York, Newark, and San Francisco are especially burdened by AIDS. Like other disaster victims, they should expect government-directed assistance from those who are spared or at least less threatened.

The measure of community is not the sharing of risk but the effective management of hazards that may or may not be evenly distributed within a population. There are opportunities to reduce anxiety and risk for all, but these opportunities are not realized by denying the existence of dangers or ignoring the possibility of risk avoidance. Instead, to seize these opportunities, we must acknowledge and use the many motivations that guide behavior in society, altruism being only one of them.

In the United States the justification for favoring community responsibility for blood has been that it is safer than other arrangements. But that is not the case in at least some locations. What is necessary is to make blood use safer for all, for friend as well as stranger. Protecting organizations that hold small empires and convenient ideologies does not reduce the risk of transfusion or build community. Finding ways to give reassurance to those who must have transfusions is the more responsive and responsible course to take in serving the community.

A POSTSCRIPT ON AFRICA

An analysis of the impact of AIDS on blood banking would be incomplete without a comment on the situation outside the United States, but especially in Africa, the other epicenter of the AIDS epidemic. In most industrialized countries, the threat of AIDS is likely to lead to improvements in blood banking similar to those achieved or on the horizon in the United States, the result of reductions in blood use and the close scrutiny of organizational structures and procedures. In blood banking at least, the AIDS epidemic has forced

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an examination of professional conduct and can be said to have induced some changes too long delayed.

The magnitude of economic and health problems affecting most African countries, however, makes any gains in blood-banking practice, even if attainable, seem inconsequential in the quest for societal progress. Persistent poverty limits the ability of these countries to provide minimally adequate medical care, including transfusion services, to large portions of their populations. The prevalence of malaria, malnutrition, and other health problems causes widespread anemia and thus increases the per-patient need for transfusions much beyond that of the industrialized world. Add to these conditions the rising number of AIDS antibody positives being found among blood donors, and the potential for disaster is greatly enhanced.[34]

Blood-banking organizations in Europe and elsewhere have expanded their established programs to provide assistance to counterpart agencies in Africa. These organizations supply disposable needles, sterilizing equipment, and the staff training needed to help quell the spread of transfusion-related AIDS. With some success, efforts are being made to develop cheaper, faster, and easier ways to administer AIDS antibody tests so as to permit more effective screening of blood donors at sites where medical capabilities are limited.[35] But there should be no expectation that these necessary activities will have much impact on the overall AIDS situation in Africa given underlying conditions.

The fear of AIDS divides communities everywhere as subgroups seek safety through isolation from one another. When the dividing lines coincide with national boundaries, political realities will make policies that reduce the risk for all unlikely. One is left with the still distant hope for a scientific breakthrough in AIDS research and the recognition that diseases are not the only destroyers of life.

ENDNOTES

[1]The precautions needed to limit exposures go beyond gloves and masks and are described in Centers for Disease Control, "Recommendations for Prevention of HIV Transmission in Health-Care Settings," *Morbidity and Mortality Weekly Report* 36 (suppl. no. 2S) (21 August 1987).

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[4]Gina Kolata, "Hemophilia and AIDS: Silent Suffering," *New York Times*, 16 May 1988, 1.

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[6]Centers for Disease Control, "Safety of Therapeutic Products Used for Hemophilia Patients," *Morbidity and Mortality Weekly Report* 37 (29) (19 July 1988): 441–44 ff.; and Margaret W. Hilgartner, "AIDS and Hemophilia," *New England Journal of Medicine* 317 (18) (29 October 1987):1153–54.

[7]Alvin Drake, Stan Finkelstein, and Harvey M. Sapolsky, *The American Blood Supply* (Cambridge: M.I.T. Press, 1982), especially chap. 4.

[8]Clark, 568.

[9]Office of Biologics, U.S. Food and Drug Administration, *Recommendations to Decrease the Risk of Transmitting Acquired Immune Deficiency Syndrome (AIDS) from Blood Donors* (24 March 1983); and Centers for Disease Control, "Prevention of Acquired Immune Deficiency Syndrome (AIDS) Report of Inter-Agency Recommendations," *Morbidity and Mortality Weekly Report* 8 (4 March 1983).

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[11]Reuben A. Kessel, "Transfused Blood, Serum Hepatitis, and the Coase Theorem," *Journal of Law and Economics* 17 (2) (October 1974):265–89.

[12]For a more detailed analysis of the structure and performance of blood banking in the United States, see Drake et al.

[13]Richard M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (New York: Pantheon Books, 1973).

[14]Harvey M. Sapolsky and Stan Finkelstein, "Blood Policy Revisited," *Public Interest* (Winter 1977):15–27; and *Hepatitis From Blood Transfusions: Evaluation of Methods to Reduce the Problem*, report of the comptroller general of the United States (Washington, D.C.: General Accounting Office, 13 February 1976).

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[16]Harold M. Schmeck, Jr., "Scientists Seek Ways to Limit Lasting Harm of Hepatitis Infection," *New York Times*, 19 May 1988, B-15; and Janice Hopkins Tanne, "The Other Plague," *New York Magazine* (11 July 1988):34–40.

[17]Gilbert M. Clark, ed., *Legal Issues in Transfusion Medicine* (Arlington, Va.: American Association of Blood Banks, 1986); Lynn Shodahl, "Liability for Transfusion-Transmitted Disease," *William Mitchell Law Review* 14 (1988):141–67; David A. Roling, "Transfusion-Associated Acquired Immuno-

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Barbara O. de Zalduondo, Gernard I. Msamanga, and Lincoln C. Chen

AIDS in Africa: Diversity in the Global Pandemic

MUCH OF THE WORLD'S KNOWLEDGE about the acquired immunodeficiency syndrome (AIDS) and its causal agent, human immunodeficiency virus type 1 (HIV-1) has been generated in the industrialized countries of North America and Europe, where AIDS was first recognized as a distinct and fatal new disease. Yet because of differences in the epidemiology of HIV,[1] the higher prevalence of other health threats, and the scarcity of health resources, the AIDS pandemic weighs more heavily on some African, Latin American, and Caribbean countries than on the West. Indeed, while the same virus is responsible for AIDS worldwide, major regional differences are observed in AIDS risk factors, clinical presentation, and care for the affected as well as in the social and economic impact of the virus.[2]

More knowledge and action are urgently needed in every country in order to cope with AIDS and contain its spread. Information deficits are particularly acute in developing countries, where short-

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falls in health services have made investment in health research a low priority. International contributions of scientific and financial resources can help developing countries meet their service and research needs. Yet not all knowledge about AIDS can be transferred from industrialized countries to other settings. This is partly because experience has made all countries cautious about foreign involvement in sensitive national problems.[2] In addition, the causes and consequences of AIDS in each country reflect the interaction of the universal (the pathobiology of HIV infection) with the unique (the highly variable health and sociocultural conditions of the populations exposed to the virus). Irrespective of the lack of affordable therapeutic drugs and a vaccine against HIV, these contextual factors are of overriding significance for AIDS prevention and care. Yet people from one country or culture all too often lack understanding of the social context of health and disease in another.

These considerations, we suggest, underscore the value of developing a global perspective on the AIDS pandemic. The objective of this article is to highlight key epidemiological differences between AIDS in African countries and AIDS in the United States, and to describe some of the background conditions that permit and constrain responses to the epidemic. While this article cannot possibly depict the many dimensions of AIDS in any country, it can convey a sense of the benefits and the challenges of cooperation with African and other developing countries in our common fight against AIDS.

EPIDEMIOLOGICAL CONTRASTS

The current epidemiological picture of AIDS in Africa must be inferred from a mosaic of disparate data—ranging from the number of AIDS cases countries report to the World Health Organization (WHO), to serological studies of HIV infection in various population subgroups. In all countries affected by the epidemic, both practical and ethical constraints prevent precise determination of the prevalence and distribution of HIV infection. Nevertheless, available data from burgeoning international research efforts support several basic conclusions about the epidemiology of HIV in African countries.[3]

Countries of High and of Low Prevalence

The epidemiological record reveals—not a monolithic blight across the continent—but a highly variable distribution across African

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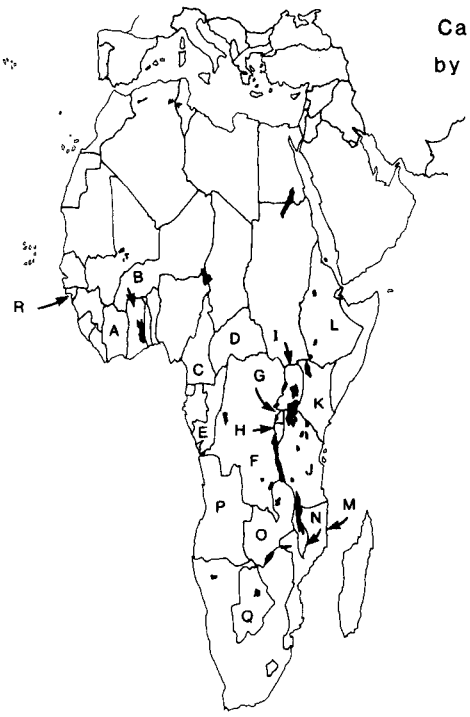
countries. This is not surprising given that Africa is a continent where 560 million people of some 2,000 distinct cultures live in fifty-one countries, all at various levels of political integration, modernization, and development.[4] By early 1989, forty-four of these countries had reported some 20,000 cases of AIDS to WHO, 15 percent of the world's total.[5]

Despite problems of "underrecognition, underdiagnosis and underreporting" of AIDS in some African countries,[6] it is clear that HIV-1 infection is presently concentrated in the central and eastern parts of the continent – in the Central African Republic, the Republic of the Congo, Zaire, Burundi, Rwanda, Uganda, Zambia, Kenya, Tanzania, Malawi, and Cameroon (see Figure 1). There are marked



Cases of AIDS reported to WHO by 12/88 per 100,000 population

A. IVORY COAST	2.24
B. GHANA	1.68
C. CAMEROON	0.58
D. CENTRAL AFRICAN REPUBLIC	15.57
E. REPUBLIC OF THE CONGO	57.34
F. ZAIRE	1.05
G. BURUNDI	28.22
H. RWANDA	15.21
I. UGANDA	53.50
J. TANZANIA	13.16
K. KENYA	12.41
L. ETHIOPIA	0.16
M. MOZAMBIQUE	0.13
N. MALAWI	34.48
O. ZAMBIA	14.80
P. ANGOLA	0.93
Q. ZIMBABWE	1.38
R. GUINEA-BISSAU	3.18

Figure 1. Diversity in Reported Prevalence of AIDS in Selected African Countries

differences between these "high prevalence" countries in the concentration of HIV and in their geography, demography, economic resources, urbanization, ethnic composition, and levels of health and

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economic development (see Table 1). Thus, generalizations about this cluster are only slightly less problematic than are generalizations about AIDS in Africa as a whole. The AIDS epidemic has reached crisis proportions in many of these nations. In the remaining three-quarters of African countries, HIV infection is not currently taking a large health toll.[7]

Recent findings in countries such as Angola, Mozambique, Zimbabwe, Ivory Coast, and Ghana indicate that fear of more widespread dissemination of HIV is well founded.[8] A second human immunodeficiency virus (HIV-2), identified in 1985,[9] has been found in some West African countries, where the prevalence of HIV-1 and clinical AIDS is very low.[10] The long-term pathogenicity of HIV-2 is uncertain and under vigorous study and debate.[11] If HIV-2 also causes AIDS—but more slowly than HIV-1—additional areas in southern and western Africa will face serious levels of AIDS morbidity and mortality in future years.

Concentration in Urban Areas

As is true for virtually all nations, the prevalence of HIV infection in affected African countries is considerably higher in urban centers of commerce than in more isolated areas. Clinic-based studies of samples of blood donors and pregnant women attending antenatal clinics or delivering in hospitals (individuals thought to be at no special risk of HIV infection) and population-based household surveys in central and eastern African cities have reported HIV prevalence rates ranging from less than 1 percent to over 30 percent (see Table 2). On average, about 20 percent of the populations of African countries resides in urban areas—and formal health-system coverage is only 10 to 20 percent in many—making urban and clinic-based samples far less representative of these countries as a whole than they are in North America and Europe, which are 70 to 90 percent urban.[12] HIV infection has decimated some rural communities in the Rakai district of southern Uganda and in the neighboring Kagera region of Tanzania—a poignant reminder that rural people are not immune to the virus.[13]

Population Distribution and Demographic Impact

The vast majority of people with HIV infection worldwide are adolescents and adults between the ages of fifteen and fifty, and

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TABLE 1. Basic Indicators for Selected Countries in Africa

Country	Population Estimated Mid-1988* (thousands)	Area*† (thousands of square km)	Number of Ethnic Groups‡	GNP per Capita, 1985	Percent of Total Population in Urban Areas*	Total Fertility Rate†	Infant Mortality Rate per 1,000 Live Births†	Child Mortality Rate per 1,000 Children†	Health Expenditure as a Percentage of Total Government Expenditure	
									1972	1985
Angola	9,481	1,247	3	—	25	0.0	137	—	—	—
Burundi	5,147	28	2	230	6	6.5	112	23	6.0	—
Cameroon	10,674	475	200	810	42	6.8	94	10	5.1	6.8
Central African Republic	2,771	623	>80	260	42	5.6	132	27	—	—
Congo, People's Republic of the	1,888	342	15	260	39	6.3	73	7	—	—
Ethiopia	44,727	122	8	110	12	6.2	154	38	5.0	—
Ghana	13,200	239	8	390	32	6.3	89	—	6.3	8.3
Ivory Coast	10,700	323	60	730	23	7.1	96	—	—	3.9
Kenya	21,100	583	4	290	20	7.8	72	16	7.9	6.7
Malawi	7,884	118	6	170	12	7.6	150	35	5.5	7.9
Mozambique	14,845	802	11	160	19	6.3	141	22	—	—
Rwanda	6,755	26	3	280	6	8.0	122	26	5.7	(4.5)
Tanzania	25,397	945	>130	290	24	7.0	106	22	7.2	4.9
Uganda	17,189	236	9	236	9	6.9	103	21	5.3	2.5
Zaire	33,755	2,345	200	170	37	6.1	98	20	2.3	1.8
Zambia	7,851	753	>70	390	49	6.8	80	15	7.4	(6.1)
United States	239,300	9,363	3	16,690	74	1.8	11	—	8.6	11.3

Sources:
*United Nations World Population Data Sheet, 1988.
†*World Development Report* (Washington, DC: Oxford University Press, 1987):
Table 1, "Basic Indicators," p. 202.
Table 31, "Education," p. 262.
Table 33, "Urbanization," p. 266.
‡George Thomas Kurian, *World Data* (New York: World Almanac, 1983).

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infants and children under the age of four. In Africa as elsewhere, there is a marked preponderance of HIV infection among people in the former, the sexually active, age range, with an overall peak prevalence in young adults.[14] In contrast with the United States and other so-called Pattern I, or industrialized, countries, where there are thirteen to twenty men for every woman with HIV infection,[15] in Pattern II, or developing, countries of Africa the sex ratio among asymptomatic and symptomatic cases is roughly 1:1.[16]

Significant deviations around the 1:1 sex ratio are detected when the data are disaggregated by age groups. In the age group fifteen to twenty-four virtually all studies report a higher prevalence in women, while in older age groups (age thirty to forty-nine) the prevalence of HIV is equal or higher among men.[17] The aggregate effects of this age-sex distribution are influenced by the pronounced "pyramidal" structure of populations in African countries (see Figure 2). As indicated in Table 1, the total fertility rate is high in most low-income African countries (despite the prevalence of sterility in some areas), as are mortality rates. High fertility results in a population structure in which nearly half the population is under the age of 15; only 20 percent of the U.S. population is in that age range. The higher prevalence of HIV infection among females in the younger sexually active age groups, amplified by the larger size of these younger cohorts, suggests that significantly more women than men are infected and at risk of HIV infection in African countries.

Pediatric AIDS

Because of the higher prevalence of HIV infection among women of reproductive age, the occurrence of HIV infection in infants is more frequent in affected Africa than it is in North America and other Pattern I regions. In Uganda, for example, approximately 10 percent of AIDS cases are seen in infants and children under age five, whereas in the United States, pediatric cases account for less than 2 percent of the national total.[18] Recent research suggests that one-quarter to one-third of the infants born to HIV-seropositive women may be infected and die of AIDS.[19] HIV is found in breast milk of women with HIV infection. While a handful of cases of transmission through breast-feeding have been documented in Africa, Europe, North America, and Australia,[20] thousands of seropositive women in developing countries have breast-fed their infants without ill result. Due

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TABLE 2. Varying Seroprevalence of Human Immunodeficiency Virus (HIV-1) in Selected African Countries

Country	Geographical Area	Reported Characteristics of Study Population	(Year of Study)	Percent HIV Positive	(Sample Size)	Reference
ANGOLA	4 Provinces	Healthy persons	(NA)	3.6%	(563)	Santos Ferreira et al., 1988 SK 5042
		Hospital and outpatient clinics	(NA)	10.0	(521)	Ibid.
	Dundo	STD clinic patients	(NA)	11.0 (Plus 3.5% coinfected with HIV-2)	(217)	Santos Ferreira et al., 1988 AR, abstract TP 16
CAMEROON	Yaounde	Blood donors	(1987)	0.28	(3,535)	Kaptue-Noche et al., "HIV Antibodies Screening . . .," in G. Giraldo et al., eds., *AIDS and Associated Cancers in Africa* (Basel: Karger, 1988).
		Women delivering at maternal and child health clinics	(1987)	1.5	(600)	Kaptue et al., 1988 SK 5125
	4 Cities	Prostitutes	(1987)	1.6	(53)	Youkokudo et al., 1988 SK 5147
CENTRAL AFRICAN REPUBLIC	Bangui	Cluster survey of adults, age 15–45	(1987)	7.8	(NA)	Gresenguet et al., 1988 SK 5032
		Prostitutes	(NA)	20.0	(NA)	Ibid.
	Bambari (described as semi-urban)	Cluster survey of adults, age 15–45	(1987)	3.7	(NA)	Ibid.
CONGO, REPUBLIC OF THE	Brazzaville	Blood donors	(1986–1987)	4.0	(13,505)	Yala, 1988 SK 5135
		Pregnant women at maternal and child health clinics	(1987)	4.0	(1,531)	Lallenant et al., 1988 SK 5028

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TABLE 2. Continued

Country	Geographical Area	Reported Characteristics of Study Population	(Year of Study)	Percent HIV Positive	(Sample Size)	Reference
ETHIOPIA	Addis Ababa	Controls	(NA)	0.0	(167)	Seyoumayehunie et al., 1988 SK 5044
		Prostitutes	(NA)	5.9	(153)	Ibid.
		Adults	(NA)	0.0	(534)	Zewdie et al., 1988 SK 5047
GHANA		National sample of patients and blood donors	(1987)	4.7	(771)	Mingle et al., 1987 DC, abstract MP.94
		Prostitutes	(1987)	25.2	(266)	Ibid.
GUINEA BISSAU	Bissau	Antenatal women	(1987)	8.5	(535)	Mendes Costa et al., 1988 SK 5009
		Family-planning attenders	(1987)	7.8	(114)	Ibid.
		Blood donors	(1987)	5.2	(189)	Ibid.
IVORY COAST	Abidjan	Pregnant women	(1986)	3.0	(331)	Denis et al., "Prevalence of Human Immunodeficiency Virus, *Lancet* i (1987):408–11
		Prostitutes	(1986)			
		Low-income		26.2	(42)	Ibid.
		High-income		14.3	(14)	Ibid.
	Tortiya	Pregnant women	(1986)	2.9	(34)	Ibid.
		Prostitutes	(1986)	6.9	(131)	Ibid.
KENYA	Nairobi	Women delivering at clinics or hospitals	(1986–1988)	2.7	(4,300)	Braddick, 1988 SK 5126
		Blood donors	(1987–1988)	2.3	(NA)	Gachuhi et al., 1988 SK 5050
		Prostitutes	(1985)			
		Low socioeconomic status		66.0	(64)	Kreiss et al., NEJM 314 (7) (1986):414–18

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TABLE 2. Continued

Country	Geographical Area	Reported Characteristics of Study Population	(Year of Study)	Percent HIV Positive	(Sample Size)	Reference
		High socioeconomic status		31.0	(26)	Ibid.
		Male STD patients	(1985)	8.0	(40)	Ibid.
MALAWI	Lilongwe and Blantyre	Unselected pregnant women	(1985–1987)	9.5	(399)	Chiphangwi et al., 1988 SK 5037
	Urban and rural	Inpatients and outpatients	(1987)	16.0	(820)	Ntaba et al., 1988 SK 5036
		Pregnant women at maternal and child health clinics	(1987)	6.5	(290)	Ibid.
MOZAM-BIQUE	9 Provincial areas	Blood donors	(NA)	1.5	(230)	Barreto et al., 1988 SK 5132
	Maputo and Beira	Random sample of adults, age 15–44	(1987)	0.9	(NA)	De la Cruz et al., 1988 SK 5056
	Nampula	Random sample of adults, age 15–44	(1987)	2.2	(NA)	Ibid.
	Northeast Mozam-bique	Displaced persons and refugees more than 17 years old	(1987)	2.9	(720)	Palha de Souza et al., SK 5151
RWANDA	Kigali	Prostitutes	(1984)	88.0	(33)	Van de Perre et al., *Lancet* i (1985):525–27
	Butare	Mothers delivering at clinics	(1987)	5.9	(286)	Ndikuyeze et al., 1988 SK 5124
TANZANIA	Dar es Salaam	Pregnant women	(1986)	3.6	(192)	Mhalu et al., 1987 DC, abstract TP.86
		Female restaurant and bar workers	(1986)	29.0	(224)	Mhalu et al., 1988 AR, abstract PS 7.3

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TABLE 2. Continued

Country	Geographical Area	Reported Characteristics of Study Population	(Year of Study)	Percent HIV Positive	(Sample Size)	Reference
	Kagera Region	Cluster survey	(1987)			Nyamuryekunge et al., 1988 SK 5034
	Urban (Bukoba)	Adults, age 15–54		32.8	(NA)	
	Rural (Bukoba)	Adults, age 15–54		0.6–9.7	(NA)	
UGANDA	Kampala	Pregnant women	(1986–1987)	20.0	(164)	Giraldo et al., 1988 AR, abstract FP 23
	Mpigi District	Cluster survey of adults	(1987)	12.2	(4,000)	Konde-Lule and Rwakaikara, 1988 SK 5039
	Rural Southwest	High risk	(1987)	67.7	(NA)	Naamara, 1988 SK 5040
		Normal risk	(1987)	17.7	(124)	Ibid.
ZAIRE	Kinshasa	Male textile company workers	(1987)	4.5	(5,971)	Kamenga et al., 1988 AR W6.6
		Potential blood donors	(1987)	7.7	(8,701)	N'Galy and Ryder, JAIDS 1 (1988):551–58
		Prostitutes	(1985)	27.0	(377)	Mann et al., *AIDS* 2 (1988):276–79
	Yambuku	Cluster survey of healthy adults, age 15–60	(1986)	0.8	(388)	Nzilambi et al., NEJM 318 (5) (1988):249–54
		Prostitutes	(1986)	11.3	(283)	Ibid.
ZAMBIA	Lusaka	Women at antenatal clinics	(1985)	8.7	(184)	Melbye et al., *Lancet* (15 Nov. 1986):1113–15
		STD clinic patients	(1985)	29.2	(144)	Ibid.

KEY. AR = abstracts from Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 1–16 Sept. 1988; DC = abstracts from Third International Conference on AIDS, Washington, D.C., June 1987; JAIDS = *Journal of Acquired Immune Deficiency Syndromes*; JAMA = *Journal of the American Medical Association*; NA = information not available; NEJM = *New England Journal of Medicine*; prostitutes = female prostitutes; SK = abstracts from Fourth International Conference on AIDS, Stockholm, 12–16 June 1988; STD = sexually transmitted disease.

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to the ambiguity of diagnostic tests that detect HIV antibodies rather than the virus itself, and possible effects of the stage of infection in the mother, the dynamics and scale of perinatal transmission are not yet clear.[21]

Factors Affecting Risk of HIV Infection

HIV infection is transmitted worldwide through the same three routes: contact with contaminated blood, sexual intercourse, and passage from mother to child.[22] The high rates of HIV reported in African countries prompted epidemiologists to look for risk factors unique to the African context. Settings, habits, and practices affecting blood contact, sex, and birth, do, after all, vary from place to place. There is extensive evidence that the conditions associated with HIV transmission in African countries differ markedly from those in the West.

Drug abuse and homosexual and heterosexual anal intercourse are not unknown in Africa, but multiple studies have failed to identify these as significant HIV risk factors in African countries.[23] Research ranging from retrospective case-control studies of AIDS patients in hospitals to population-based surveys of apparently healthy community members suggests that at least 80 percent of people with HIV infection in Africa have contracted the virus through heterosexual intercourse, whereas only 4 percent in the United States have done so.[24] Indeed, observations in central and eastern African countries provided the first strong evidence for the possibility of heterosexual HIV transmission.[25] The early years of research on AIDS occurred largely in Pattern I countries, where most cases were attributable to male homosexual intercourse or transmission through infected blood.

The frequency of sexual partner change appears to be the most robust proximate risk factor for adult HIV infection in Africa. Individuals who have had sexual intercourse with multiple partners, or whose sexual partners have, run disproportionately high risk of infection, especially in locales where communitywide HIV prevalence is low.[26] For example, studies of women identified as prostitutes have shown infection rates of 5.9 percent in Addis Ababa, Ethiopia; 27 percent in Kinshasa, Zaire; and 66 percent in Nairobi, Kenya. The "background" prevalence of HIV in these cities in 1987-1988 was approximately 0, 6, and 2 percent respectively (see Table 2).

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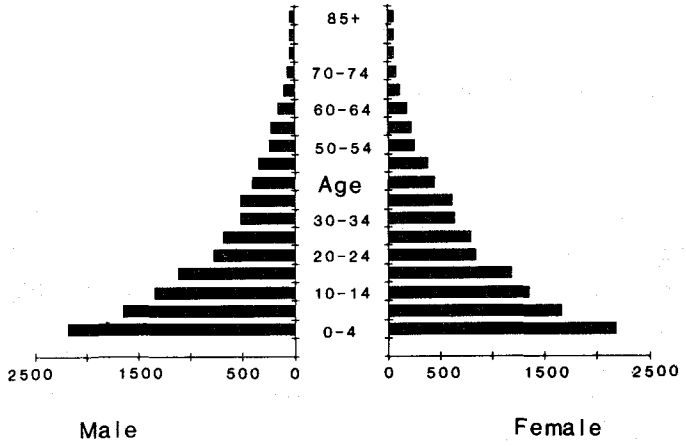
a. Distribution of population by age and sex in Tanzania, 1988, in thousands



b. Distribution of population by age and sex in the United States, 1988, in thousands

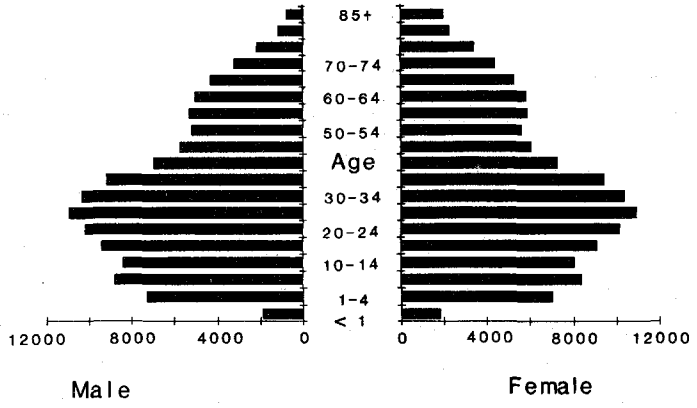


Figure 2. Demographic Structure of a High-Fertility and a Low-Fertility Population

Sexually transmitted diseases (STDs) have been identified as important risk factors for sexually acquired HIV infection in Pattern I and II countries alike.[27] Case-control epidemiological studies have

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demonstrated that infections which cause genital ulceration, such as syphilis, herpes simplex type II, and chancroid, may facilitate sexual transmission by increasing an HIV-seronegative partner's vulnerability to infection, and perhaps also by increasing the infectivity of HIV-seropositive sexual partners.[28] Simonsen and colleagues' study of HIV seropositivity among 340 men attending an STD clinic in Nairobi observed an odds ratio of 7.2 for those who had genital ulcers in comparison with those who did not.[29]

Scarification, circumcision, and therapeutic injections involving unsterile equipment do not appear to be significant risk factors in Africa, although such practices certainly could transmit HIV and could play a larger role in the future.[30] Blood transfusion is a common hospital procedure in Africa because of the high prevalence of anemia due to hemorrhage, nutritional deficiency, and malaria. Epidemiological studies indicate that contaminated blood transfusion may account for as much as 10 percent of infections in African countries, whereas in the United States it accounts for only 0.3 percent.[31]

Health Systems and Clinical Care

Differences in the availability of health services, as well as in the spectrum of pathogens in industrialized and developing-country environments, influence the clinical presentation of AIDS and the interaction of HIV infection with other health problems. Together, these complicate AIDS diagnosis and care in Africa.

High rates of STD have been found in many areas of sub-Saharan Africa, even in "low risk" samples.[32] For example, one comparative study shows that 10 percent of women in Kampala, and 7 percent in Nairobi, had gonorrhea, whereas London had only 0.003 percent.[33] The lower prevalence of these curable "cofactors" of HIV in America and Europe is due both to greater access to curative services and to active public health surveillance, including tracing and treating sexual partners of infected persons. Thus, the relative weakness of modern health-care systems, as well as behavior patterns that increase the risk of exposure to STDs, influence HIV spread. It has also been suggested that prior infection with HIV may be increasing people's vulnerability to STDs.[34] Since AIDS education has increased general awareness of STD, population-based monitoring is needed to distinguish increases

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in STD prevalence from increased treatment seeking and increased medical detection and reporting.

Active HIV infection makes people vulnerable to a wide range of human pathogens and thereby increases the demand for medical services by seropositive individuals. In some high-prevalence African cities, nearly 40 percent of the hospital beds are occupied by HIV-1 positive individuals who were admitted for other conditions, such as tuberculosis.[35] If HIV-seropositive individuals more easily develop active tuberculosis infections, for example, they may also increase the exposure of HIV-seronegative individuals to pathogenic organisms that are life threatening in their own right.[36]

In East Africa, AIDS is often given the name "Slim" because many of its victims die after progressive weight loss and diarrhea due to pathogens attacking the gut, without the distinctive respiratory infections or carcinomas that often signal AIDS in the United States. The major signs of AIDS in the African context (enormous weight loss, sustained fever, prolonged diarrhea) are also symptoms of tuberculosis, malaria, and other curable infectious and parasitic diseases, which together account for more than 50 percent of the adult morbidity in African countries.[37] Clinical diagnosis of AIDS in children is particularly difficult because key symptoms of pediatric AIDS in Africa (diarrhea, wasting, and "failure to thrive") also are symptoms of malnutrition, which affects more than 20 percent of the children in many low-income areas regardless of their HIV antibody status.[38]

Because few facilities in developing countries have the laboratory equipment and staff needed to meet the Centers for Disease Control case definition of AIDS (this requires ruling out causes of immune suppression other than HIV), WHO developed a revised clinical-case definition for Africa with the hope of minimizing underdiagnosis and underreporting. When applied outside specialized hospitals in high-prevalence cities, however, this new definition may have a specificity as low as 50 percent.[39] That is, between 10 and 50 percent of the patients who meet the revised clinical criteria for AIDS do not have HIV infection but some other illness. Even the most experienced diagnosticians in Africa now maintain that definitive diagnosis of AIDS requires confirmation of HIV seropositivity.[40] This requires a series of HIV antibody tests that are expensive and largely unavailable outside urban centers.

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The need for serological confirmation is not a mere technicality. Unlike the United States, where most people diagnosed with AIDS can expect to receive hospital care and follow-up, many African physicians despair of being able to provide palliative treatment for people with AIDS, especially over the long term as caseloads increase. Expensive drugs such as AZT are out of reach for all but the wealthy few. It is often said that people with AIDS are "sent home to die." The connotations of this phrase are not necessarily negative in societies where nurturance, support, and healing are associated more with home than with hospitals. Nevertheless, under such circumstances, overdiagnosis means that people with curable conditions such as tuberculosis may be sent home without treatments that are available. If AIDS becomes the diagnosis of first rather than last resort, as rumors have it in some high-prevalence areas, the label may become as lethal as the disease itself.

Together, these facts intensify the health impact of AIDS in Africa and alter its meaning for health-care providers. In many high-prevalence countries, seropositive individuals are not informed of their serostatus because their numbers far outstrip the health system's capacity to provide counseling services and because what such services should be and how to offer them is not clear. Testing patients prior to surgical or obstetric procedures is impractical, even where facilities to do so are available. Shortages of surgical gloves and other supplies make "universal precautions" to avoid infection out of the question in both modern and traditional health-care settings, so that caregivers are at substantial risk of exposure to the virus. Moreover, under conditions of scarcity, providing palliative care to prolong the life of a person with AIDS may actually prevent saving the life of another with a curable condition. Where is the boundary between treatment and triage, and how and by whom should this be decided?

Social and Economic Impact

Thousands of people will die of AIDS in the high-prevalence areas of central and eastern Africa. Peter Piot and colleagues have estimated that 5,000 deaths per million sexually active adults per year are occurring where levels of HIV-1 infection are only 5 percent.[41] In heavily affected countries, AIDS may by 1990 increase already high levels of child mortality by 25 percent, and adult mortality by 200 to 300 percent.[42]

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To African countries, the aggregate loss of productive capacity these deaths represent is the principal economic concern. Illnesses and deaths among women and men in their most productive years mean economic losses and painful decisions at both the family and the community level. They leave the children of AIDS victims seriously at risk. Traditions of extended family support cannot be expected to compensate fully for such losses, especially since historically, the flow of financial resources has been from urban to rural family members in most African extended kin networks.

For all these reasons, individuals, families, healers, and policymakers in high-prevalence African countries will be confronted increasingly with heart-wrenching ethical dilemmas that are qualitatively as well as quantitatively distinct from those faced in affluent industrialized countries. The health-care systems of African countries were under serious strain before the AIDS crisis. The proportion of government expenditures devoted to health, which ranged from only 2 percent to 8 percent in 1981 (it was 11 percent in the United States), has been declining in nearly all African countries.[43] Responding to the AIDS epidemic imposes new demands for training, education, and care at a time when national economies have been shrinking under the weight of falling export prices, ecological disasters, and crippling external debt repayments.[44] Charles Myers and Albert Henn estimate that the cumulative costs of AIDS in Zaire from 1985 to 2005 may range between $8.6 billion and $17.4 billion, which exceeds all of the foreign development assistance received by that country. However high these aggregate estimates may be, Myers and Henn point out that the projected losses due to AIDS "are not nearly as high as the cost of the negative growth rates in per capita product in the past two decades which had nothing to do with AIDS." Improved economic policies could more than offset losses at these levels over the next decade in the larger African countries.[45]

The extremely high prevalence of HIV in samples of pregnant women in some epicenter cities, and estimated "doubling times" from one to three and a half years in these areas,[46] illustrate the devastating potential of the AIDS epidemic in the African context. Yet a much larger proportion of the population in African countries is below the age of presumed onset of sexual activity and of sexual exposure to HIV.[47] Epidemiological uncertainty about the determinants of HIV transmission lead demographers to disagree on the

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aggregate demographic impact of HIV-related mortality in Africa. While Anderson and May foresee a major decline, possibly resulting in negative population growth,[48] Bongaarts predicts that AIDS will have a surprisingly weak effect on population growth over the next ten to twenty years.[49] His model projects reduction in the growth rate from 3 to perhaps 2 percent and does not support predictions of a hollowing out of the age structure in African countries.[50]

Despite the attention given cases among highly educated or elite men, it is now clear that people of all economic levels and social classes in high-prevalence African countries are at risk for HIV infection.[51] Equity brings little comfort in this context. Available data are too scant to determine the impact of economics or social class on susceptibility to infection, or on risk behaviors mediating HIV transmission. Wealth clearly mediates access to treatment services, however, and thus affects the prognosis of people with HIV infection. While present evidence does not reveal any consistent association between rates of HIV infection and wealth, social class, or ethnicity in African countries,[52] there are reasons to expect that HIV infection, like other debilitating and deadly health threats, will be found disproportionately among the poor.[53] Yet the distribution of high-risk behaviors and the personal and social linkages among Africans —with and without HIV infection—cut across economic, political, and ethnic dividing lines. Unlike the epidemic in Pattern I countries, where it is associated with behaviors and orientations that violate and threaten mainstream norms, the broad social distribution of AIDS in African countries may counter some insidious rationales for blaming and/or abandoning the victims of HIV infection.[54]

It is useful to identify commonalities and contrasts in the epidemiology and impact of AIDS in various regions. In reality, of course, a multitude of factors intersect at many levels to determine the scale and meaning of the epidemic. Thus, the social determinants and impact of the epidemic are not well understood through generalities. Description of the epidemic in one particular place may clarify the interlocking background factors that distinguish the AIDS epidemic in the West from its many manifestations in Africa.

THE KAGERA STORY

Very high HIV seroprevalence has been documented in Kagera, one of twenty administrative regions in mainland Tanzania. Kagera lies

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on the western shore of Lake Victoria, bordered on the north by Uganda and on the west by Rwanda and Burundi. Economic, kinship, and cultural ties have long linked the peoples of Kagera with those in these neighboring countries, where HIV seroprevalence is also high. Labor migration has a long history in this area. The population density reaches 1,500 per square kilometer[55] in the fertile farming areas near the lake, where the Haya (the predominant ethnic group) have tended stationary tree crops for hundreds of years. The Haya are renowned as one of the most affluent and productive people in East Africa; they domesticated coffee and were active early in the commercial coffee- and tea-growing industry that brought prosperity to the region and to the German and British colonial empires.[56]

Some distinctive features of the Hayas' traditional economy and social system seem particularly relevant to the AIDS pandemic. In pre- and postcolonial times, their complex hierarchical social organization included privileged ruling dynasties and patrilineal land-inheritance rules requiring that family farms be passed on intact to male heirs. In most polygynous, patrilineal societies girls marry early (between ages 13 and 15 or shortly after menarche) and move to their husbands' homesteads, where they achieve adult social status and economic security by bearing children for their husbands' lineage. Boys marry later partly because of the need to accumulate bridewealth, and through life men can aspire to take on additional wives as their households and resources permit.[57] Among the Haya, in contrast, the above land tenure rules effectively limited polygyny to the ruling dynasty. Women and men married quite late (Reining found the mean age of marriage to be 17.5 and 26 for women and men respectively) because of the need of most sons to find other farming land (usually on a tenant basis) on which to install wives. Reining also noted that in traditional times women of the ruling dynasty were prohibited from getting married. They were permitted to take lovers, however, and to have their own farms where they could grow plantains and other crops independently. Women in lower-status clans were valuable not only for their productive and reproductive functions: fathers could give daughters as concubines or servants, in tribute or in payment of debt. Thus, from the high and low ends of the social scale, there were precedents both for male and female mobility and for exchanging sexual services for prestige and/or economic rewards.

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In many polygynous cultures, an active sex life has been considered both a right and a requisite of good health, for women as well as for men.[58] Marriage universally confers rights over a woman's fertility to her husband, however, and so community attitudes toward a woman's extramarital affairs range from mild to extreme, punitive disapproval.[59] In general, men are required to respect their family obligations and to eschew as sexual partners the wives or prospective wives of kinsmen and women from other proscribed groups. Within these limits, little or no shame or stigma is attached to men's extramarital sexual relations, including casual encounters with "bar girls" or other sexually available women who have been drawn or driven to towns, away from the care and supervision of their own kin. Studies of married and unmarried village women in the Bukoba district indicate that a period of commercial sex work in town was a not uncommon way for women to gain cash to meet their families' needs or even to establish themselves as independent farmers.[60]

While much of the population of Kagera is devoutly Christian and monogamous today, cultural legacies are rarely discarded completely. Conflicts between formal moral teachings (e.g., on the virtues of monogamy or faithfulness) and internalized, felt beliefs about behaviors that define "good" versus "bad" people are prime features of cultural change, be it in African, American, or other settings. Both the economic and the sociocultural conditions of life have been changing rapidly in Kagera since the 1920s, when schools, church missions, and other modernizing influences began escalating development in the region.[61]

Tanzania is rich in economic potential and developed human resources, but national and international economic policies and the 1978-1979 war with Uganda had a devastating effect on its economy and quality of life. The Kagera region was particularly hard hit by these largely exogenous political and economic forces. Restrictions on foreign-currency exchange and imports and the scarcity of essential household commodities as well as luxury goods in the late 1970s and early 1980s increased the incentives for people to travel and trade with countries where goods were in greater supply. Before AIDS was called "Slim," it was referred to as "Juliana" in Tanzania, named after a brand of illegally imported clothing that for a while was a status symbol among young men who were successful in the illicit cross-border trade.[62] Unlike the majority of the population, whose

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subsistence activities and cash-crop production were disrupted in the late 1970s and early 1980s, the Juliana traders had cash and access to valued goods that could not be obtained locally for any price. In their home communities and along the trade routes from Burundi and Rwanda to Uganda and beyond, the traders could sell or exchange these valuables for other items, including lodging, food, beer, and companionship as well as the sexual services of women.

In Bukoba, one of Kagera's five districts, curable STDs were, after malaria, the second most common diagnosis in outpatient clinic care in 1985.[63] In keeping with Tanzania's ideology of socialism and self-reliance, the government has built perhaps the most extensive network of rural schools and health clinics on the continent. However, the share of the government's operating budget allocated to the health sector has declined by 50 percent since 1976. This decline has limited purchasing power for most of the district health facilities. As a result, antibiotics and other essential supplies have not been easily available. This development in turn undermined earlier efforts to bring STDs into check and may have left women and men more vulnerable to HIV infection.

No one knows when or where HIV was introduced into Kagera, or whether the Juliana traders were the first bearers of the virus. The first Tanzanian cases of AIDS are thought to have appeared in Kagera in 1983, a year after AIDS was first diagnosed in a nearby region of Uganda.[64] Our colleagues from Muhimbili Medical Center in Dar es Salaam report that, through association with the sexually active young people who were its first victims, the people of Kagera first believed the novel, deadly syndrome was sexually transmitted. But as time went on, this folk wisdom was rejected, for individuals who were not perceived to be at risk for STD were seen to fall ill with Juliana or Slim, while others known to engage in multiple sexual encounters remained symptom free.[65] Because of the difficulty of communication with specialists in the capital hundreds of kilometers away and the lack of facilities in Kagera for diagnosing AIDS in the pre-ELISA era, the national medical community did not become fully aware of the crisis until late in 1985, when serological tests for HIV antibodies became available. By this time, the virus was firmly entrenched in the population.

In 1986, a longitudinal, multidisciplinary study was launched to define the epidemiology and social impact of HIV infection and AIDS

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in the region and to guide a vigorous prevention program.[66] A population-based cluster survey in Kagera's Bukoba district begun in 1987 shows that the mean prevalence of HIV in the adult population of this largely rural area was 11.9 percent in mid-1988 and in children 3.9 percent. However, in the town of Bukoba, 32.8 percent of the adult population tested positive for HIV, the highest age-specific prevalence—41 percent—being found in individuals age 25 to 34 years old.[67] Rates were higher in women in the urban area. In the rural zones sampled, prevalences ranged between 0.6 percent and 9.7 percent, and rates among men were double those found among women. Risk of HIV infection was related to reported frequency of sexual partner change, and for rural dwellers, to travel outside the region. Individuals reporting more than one partner in the last eight years were at substantially higher risk of HIV infection than were others.[68] This lends epidemiological support to the argument that *promiscuity* is not an appropriate descriptor for high-risk behavior in Kagera.

The social and economic impact of AIDS in the Kagera region has been devastating, and it will get worse as most or all of those with HIV infection develop AIDS-related complex and AIDS. Some have reported the loss of entire families and the collapse of businesses and other enterprises. Orphans, who would be cared for by relatives under normal circumstances, have been abandoned out of necessity. Some have been shunned out of ill-founded fear that the children of AIDS-afflicted parents might carry and convey the killing disease. In Kagera and in other places where the prevalence of AIDS is high, fear, misinformation, and resignation interfere with prevention efforts.

The despair of married women is particularly acute, for without the cooperation of their husbands, they cannot protect themselves. Yet it is not customary for wives to speak directly with their husbands about sexual matters. Being both economically and socially dependent on her husband and his kin, a wife precipitates domestic conflict at her peril. Hopelessness can undermine the will to adopt preventive measures, despite the availability of means to do so: among the most heavily affected age groups in Bukoba, chances are more than even that a given individual is not infected.

It is believed that the sexual relations of traders and other travelers account partly for the dissemination of the virus to Dar es Salaam, where the seroprevalence in adults of reproductive age was estimated

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to be 3 percent in 1987 and 3.7 percent in 1988.[69] Some also say that Haya women are so beautiful that they are sought out as sexual partners despite the high risk that they could transmit HIV. The Ugandan military invasion in 1979 and the subsequent Tanzanian military response may have been far more important than trading practices in the dissemination of STDs and HIV in Kagera. From 1979 to 1982 soldiers, mostly outsiders unconstrained by local traditions, occupied the high-prevalence area that spans the border and then went home. Thus, the past and present political and economic environment as well as a people's "sexual culture"[70] bear heavily on the current distribution of HIV and will continue to affect its course. Knowledge of such forces that link peoples, countries, and regions—when meshed with knowledge of the distinctive history and lifeways of a specific area or people—provide the sense of place that is essential for interpreting epidemiological findings and for translating universal AIDS-prevention tactics into locally appropriate forms.

PSYCHOSOCIAL, ECONOMIC, AND HEALTH-SYSTEM FACTORS

The Kagera story, even in this impressionistic sketch, illustrates several additional interactions that produce diversity in the AIDS pandemic. It is misleading to view the concentration of HIV infection in urban areas as a gradient, implying random diffusion of HIV from high-prevalence urban to low-prevalence rural areas. With the exceptions of contaminated injections and blood transfusions, the spread of HIV maps person-to-person sexual contact, which is distinctly nonrandom. Cultural rules as well as individual inclinations, and economic as well as situational factors, affect both the availability and the definition of acceptable sexual partners. Indeed, just as HIV prevalence is uneven at the macrolevel—among countries—so striking variations in HIV prevalence are observed at the microlevel—within zones of Kagera, even in adjacent rural communities. This unevenness is not unique.[71] The clustering of AIDS at the level of families and neighborhoods is to be expected everywhere, for people tend to associate and reside preferentially with similar others.[72]

Given the complex mosaic of cultures and of high- and low-prevalence areas in Africa, rational allocation of resources and design

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of appropriate AIDS interventions are far more difficult to achieve there than in the United States. Traditional social organizations in Africa tend to define communities and family responsibilities more by networks of kinship and lineage than by occupation or residence. These networks support indelible emotional and economic bonds that promote the regular movement of people between their communities of origin and their urban workplaces and markets.[73] Therefore, the places most urgently in need of AIDS prevention and care services must be identified by the subtle determinants of social and economic distance as well as by geographical proximity to national and regional epicenters of HIV infection. Without rapid expansion of AIDS education and services into more distal regions, particularly along truck routes and other major arteries, the low prevalence of HIV infection in rural areas of high-prevalence countries may be short-lived.

Available information about sociocultural variation and linkages between communities in Africa is often sequestered in social science publications that are not familiar or accessible to health-care planners and providers in Africa—or to their expatriate collaborators. In the United States and other countries of the West, decades of population-based sociological and anthropological research have demonstrated the value of such information for improving health services and for interpreting efficient, clinic-based research.[74] Economic and ethnic differences are known to affect the social and sexual mixing of population subgroups, the health risks in people's environments, their beliefs about health, their use of health services, and their responses to biomedical information and care. For such reasons, it would have been unthinkable for U.S. AIDS researchers to generalize rates of HIV infection found in inner-city New York hospitals to the whole United States or all of North America. Headlines in the Western press in 1986 and 1987 were based on this kind of error: saying that "Africa" was "dying of AIDS" reflected a lack of understanding of the heterogeneity within and across African countries.

It is also misleading to assume that communities beyond the reach of Western biomedical facilities exist in a health-care vacuum. Every society and culture has systems for diagnosing and treating illness according to prevailing understandings about health and disease. While the efficacy of biomedicine for curing some health problems is

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not lost on rural ethnic groups, traditional healers provide most of the health services in developing countries.[75] Low access to biomedical services is only part of the reason. More important is that people seek out and follow therapies they value and understand. AIDS-prevention programs in all countries need information about folk medical systems if they are to penetrate the assumptions and fears that shape people's responses to health information, including information about HIV transmission and prevention.[76] Discrepancies between biomedical and folk views of the causes and risks of illness, including AIDS, are more obvious in developing countries where only a minority participate in the modern culture of which biomedicine is a part. Yet these discrepancies exist all over the world.[77] In the absence of a cure for AIDS, understanding and working with community concepts of health, including healthy sexuality, are more crucial than ever.[78]

Differential sexual license is a legacy that many men are loathe to relinquish. In most parts of Africa, however, women's social status and autonomy are particularly low, and educational and employment opportunities reflect pronounced gender bias.[79] Thus, women in Africa have far less power to promote and enforce "safer sex" guidelines than do those from North America or Europe. Schoepf, Rukarangira, and colleagues, working in Kinshasa, report that many married women fear beating or divorce if they refuse sex or press their husbands to use condoms and that wives have even less leverage to promote reductions in their husbands' extramarital affairs. Unmarried or abandoned women often have children to support. To complement the small earnings that may derive from unskilled work or trading, women who seek freedom or refuge in towns often have little choice but to develop informal sexual relationships with men. Such relationships vary from long-term common-law marriages to the fleeting impersonal commercial transactions defining prostitution.[80] Superimposing dichotomies from the West (such as "prostitutes" as opposed to "faithful wives") on this spectrum of sexual-economic exchange relationships obscures important differences in the social meaning, the determinants, and the epidemiological implications of diverse multiple-partner sexual relations. Yet across this spectrum, the danger of HIV infection has turned an age-old economic survival strategy into "a death strategy" for urban

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African women[81] and has magnified—indeed transformed—the risks of liberal sexual norms for men.

Clearly, AIDS increases the need to include education, counseling, and support services in public and private health-care systems and to introduce these in situations where no modern health infrastructure exists. In all African countries today, however, many health problems are quantitatively more important than AIDS, so that marshaling the political will to invest adequately in AIDS prevention is difficult. There are from 400 to 1,000 cases of malaria for every case of AIDS in high-prevalence countries, for example,[82] and untreated malaria can be as fatal as HIV infection. In addition, macroeconomic trends, rapid urbanization, the urban concentration and male bias of education and job opportunities, labor migration, intranational as well as international ethnic conflict, war, and other conditions that disrupt families and communities all impede the delivery of health information and health services.[83] They also increase the number of people living in environments that permit and/or promote high-risk sexual behavior.

If there are grounds for concern about the continent of Africa as a whole, it is because these sociocultural, economic, and health conditions are widespread.[84] The social infrastructure is in place for rapid intra- and international dissemination of sexually transmitted diseases, including AIDS and HIV. To take early preventive measures in all African countries where such conditions occur is therefore reasonable.[85] Because biomedical health systems are already overburdened with the treatment of other more prevalent illnesses, however, AIDS prevention and care in African countries cannot be strengthened by diverting resources from other health priorities. New internal and external resources must be harnessed to complement and strengthen existing health and social services.

RESPONSES TO THE CHALLENGE OF AIDS

The kind of national and global response the AIDS epidemic has evoked is unprecedented[86] At the international level, WHO inaugurated the Global Program on AIDS (GPA) early in 1987. The GPA, working in concert with multilateral organizations such as the United Nations Development Program, the World Bank, and UNICEF, and with numerous nongovernmental organizations around the world,

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has played a vital role in raising international awareness and acceptance of the disease threat and in coordinating programs to combat it. All member states of WHO's Africa region have formed national AIDS committees to assess their countries' AIDS situation, and over half have formulated national medium-term plans to guide action by their National AIDS Control Programs over the next five years. Donor consortiums, coordinated by the GPA, have pledged to augment their support of existing health programs with new funds for many of these national plans, at levels ranging from $2 million to $8 million in U.S. currency for the first year.[87]

This amount of cooperation and coordination across countries and sectors is in itself a substantial achievement. It has produced impressive results at the national as well as the international level. For example, the GPA anticipates that all African countries will have blood screening in place in their major cities by 1989.[88] As the blood-bank screening initiatives have shown, many scientific and technical resources for AIDS interventions are transferable from one country to another. AIDS-affected countries all over the world have many challenges in common. The battles against discrimination and misapprehension about HIV infection,[89] the quest for therapies and for a preventive vaccine, increasing the representation of women in health policy and program design, and transcending barriers between the social and biomedical sciences in health research are only four examples. However, prevention strategies reflect the country-specific epidemiology of HIV infection, what is theoretically possible in the way of AIDS prevention and care, and what can be done immediately to control the epidemic, given the human, technical, and financial resources that are available. It is not surprising, therefore, that differences emerge in countries' responses to AIDS in Africa and the West.

Preventing perinatal transmission, for example, is of far higher priority in African countries than in the United States because Africa has a higher prevalence of pediatric HIV infections and because widespread pronatalist values there make it easier to achieve consensus on interventions promoting healthy childbearing than on other scientifically indicated strategies, such as STD control. In the United States, seropositive mothers are discouraged from breast-feeding because the risk of transmission through breast milk is greater than zero and because safe alternatives are assumed to be available and affordable. The alternatives for low-income women, especially those

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in developing countries, are actually quite limited: substitutes for breast milk are costly, and they carry very high risks of other life-threatening infections, which are far more prevalent than HIV. For this reason, WHO, UNICEF, and other authorities strongly support breast-feeding by all women in developing countries, regardless of their HIV serostatus.[90]

Clearly, the preferred way to prevent perinatal transmission is to prevent HIV infection in women by reducing exposure to contaminated blood and inducing couples to follow safer sex practices. Failing primary prevention, sexual abstinence, use of contraception, and termination of pregnancy will curtail perinatal transmission. The use of contraceptives in African countries, however, averages 11 percent—lower than anywhere else in the world—and condoms are the least popular contraceptive method of all. Skeptical about the chances for rapid change in adults' sexual behavior, some high-prevalence African countries are adopting vigorous programs to provide sex education and/or AIDS education for school children, who may be more amenable to prescriptions for a future of mutually faithful monogamy or condom use.[91]

All these tactics for preventing sexual and vertical transmission of HIV are controversial in Africa, just as they are in America. Furthermore, over the long term, "covering the continent with latex" is neither a practical nor an affordable solution. Aside from issues of distribution and disposal of condoms, experts at the GPA estimate that their annual cost (assuming two condoms per week per couple) exceeds $18 per couple in African countries.[92] Yet sex education, contraception, and avoidance or prompt treatment of STD all contribute to reproductive health, which includes the ability to bear and raise healthy children—an important value for men and women worldwide. The infusion of resources for AIDS education, and an entirely new level of interest in mobilizing the behavioral sciences in this endeavor, may induce individuals and opinion leaders not to ignore norms regarding sexuality and reproductive health but to engage and reconfigure them to cope with the long-range challenge of living with AIDS.

To promote such changes, several national AIDS-control programs have made use of social marketing techniques to disseminate AIDS information to the public. Popular awareness of AIDS has increased dramatically in cities such as Kinshasa, Kampala, Lusaka, Kigali, Dar

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es Salaam, Brazzaville, and Nairobi, where from 65 percent to 98 percent of survey respondents have now heard of AIDS.[93] These mass-education campaigns have faced many of the problems observed in the United States and Europe—often in intensified form.[94] Furthermore, it is well known that knowledge of AIDS is only one of several requirements for health behavior change,[95] and as we have noted, perceptions of illness and available means to avoid it vary greatly from culture to culture. While marketing techniques have increased recognition of the term *AIDS*, so far there is little evidence that mass-media campaigns alone have led to significant changes in AIDS risk behavior in Africa any more than they have in North America or Europe.[96] Evidence from small community-based pilot programs is encouraging, although these rarely report formal evaluation measures. For example, The AIDS Support Organization (TASO), a volunteer group in Kampala, Uganda, was founded by women who have lost family members to AIDS.[97] TASO offers counseling for the families and communities of AIDS sufferers, including education about HIV transmission and means of protecting caregivers from infection. In Kinshasa, Zaire, Projet CONNAISSIDA has developed "action research" methods for use in small self-selected community and church groups, where many of the problems of cross-sex, cross-age, and cross-cultural communication about sexuality are overcome.[98] Pilot education programs are working with groups of urban women who sell sex in Nairobi, Kenya, in Kinshasa, Zaire, and in Accra, Ghana.[99] These programs show that even individuals whose risk behavior is sustained by overriding economic pressure are motivated and able to protect their health through the proper use of condoms.

Community projects for individuals are more time and labor intensive, and thus more expensive per person served, than are mass-education campaigns. National programs to train people such as school teachers, health-care providers, and community leaders are being launched in several countries so as to multiply the benefits of investment in AIDS education. Their evaluation thus far reflects a narrow, short-term view of the costs, benefits, and contextual determinants of program results. More comprehensive and heuristically useful evaluation methods are needed for measuring and explaining the cost-effectiveness of the myriad interventions under way in high-prevalence countries around the world. Small-scale projects are

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likely to be increasingly important pillars of AIDS prevention and care in all high-prevalence countries. Within culturally homogeneous communities, trained staff can translate AIDS information into locally meaningful terms and can anticipate and respond to the social, economic, and health concerns that affect the acceptability of recommended actions. Perhaps most important, projects generated and staffed by community members and existing health-care providers are more likely to be sustained after national and international technical assistants have gone home.

WHY SUPPORT AIDS PROGRAMS IN AFRICA?

Two rationales exist for the United States and other industrialized countries to support AIDS research and interventions in developing countries, including those in Africa. First, the United States is a rich country, and sharing this bounty with others is, in principle if not in practice, an important cultural ideal.[100] The AIDS pandemic will test Americans' representation as a generous people: funds as well as sympathy are required to provide the medical, educational, and social services needed to mitigate suffering caused by the epidemic both at home and abroad.

Second, the United States' self-interest is in numerous ways at stake in AIDS control in the developing world. Viruses do not respect national boundaries. History has shown that isolationism is a poor national defense against infectious disease.[101] Due to the unique biological characteristics of the virus, quarantine and related strategies would almost certainly be ineffective, and any attempt to implement them would require all Americans to surrender liberties and guarantees that are highly prized.

Other United States interests are also at stake. It is in Americans' interest to protect commercial investments overseas and to promote the safety of travelers and people in government service stationed in developing countries.[102] It is in the West's geopolitical and strategic interest to prevent the potential social and political destabilization of African countries that might follow massive mortality from AIDS. In addition, opportunities for mutual learning arise as all countries marshal their creativity and expertise to cope with AIDS. Policies and programs on AIDS are being attempted around the world, each with some contribution to make to global knowledge about effective AIDS

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prevention and care. It does not make sense for countries to repeat others' mistakes in isolated battles against AIDS.

Furthermore, there are pressing issues in AIDS control that the United States cannot address alone. The surprise with which Western AIDS researchers "discovered" heterosexual transmission in Africa in 1986 illustrates the value of a comparative view. Like heterosexual transmission, questions concerning perinatal transmission are difficult to explore in Pattern I countries, where the prevalence of infection among women is so low and where a large proportion of those affected are either intravenous drug users or the partners of intravenous drug users who have numerous other social and health problems. In terms of prevention and care, the potential benefits of alternative therapy systems in providing culturally appropriate, affordable care are difficult to analyze in industrialized countries, where such systems are less visible and pervasive. Just as study of the feminist movement may provide alien but practical lessons for African policymakers to consider, so health planners in the United States need to understand the operation of health systems where the bulk of care is provided and financed by community members and where specialists have less power over the definition and costs of treatment.

There is also serious question whether the appropriate testing of an AIDS vaccine—should one be developed—could be successfully carried out without international cooperation.[103] To be effective, vaccine trials must be conducted in populations that are not infected but significantly at risk of infection, that are willing to participate in a relatively high-risk study, and that can be followed up and restudied over time. For reasons that Nicholas Christakis has enumerated,[104] such populations will be far easier to identify in high-prevalence African cities than in the United States. Seroprevalence data suggest that individuals in those cities (along with intravenous drug users in Pattern I countries) have the most to benefit from an effective vaccine. Yet enormous ethical concerns and conflicts are suggested by the image of Americans testing AIDS vaccines in Africa. As Christakis has suggested, negotiations can be conducted up front to prevent indefensible inequities in the distribution of risks and benefits derived from such research.

However, given the West's poor track record on transferring the economic and institution-building benefits of research to developing-

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country partners, Americans should not be surprised if potential collaborators in Africa fear the worst. U.S. financial and technical support for AIDS research and prevention by Africans in their own countries may give new credibility to invitations for coequal participation in vaccine trials and other research in which we have a joint interest.

* * *

The AIDS virus is but one of the many organisms that compete with humankind for a niche in the world. Just as the HIV virus seemed to appear out of nowhere, so too there are other organisms evolving in, or in relation to, human populations that are, in turn, in dynamic interaction with each other and with other aspects of their environments. The full consequences of shifts in these complex ecological relationships cannot be anticipated in advance. Thus, it is highly likely that HIV is not the last fatal organism that will emerge to attack human populations. How the global community copes with the AIDS epidemic will serve as a model for responses to similar threats in the future as well as a guide for future phases of the current epidemic.

For high-prevalence Pattern II countries, the risks and demands of living with AIDS are more acute and far-reaching than they are at present in Pattern I countries. Initiatives to respond to AIDS cannot alone be expected to solve the broader problems of economic and social development, although the vulnerability of all socioeconomic groups to this new threat could provoke new efforts to overcome internal impediments to these broader goals. The global need to cope with and combat AIDS has raised the incentive to overcome barriers between disciplines, between cultures, between classes, and between countries, for all of these barriers slow progress in understanding and coping with AIDS. Jonathan Mann, director of the Global Program on AIDS, has rightly said, "For AIDS to be conquered anywhere, it must be conquered everywhere." It is in the interest of industrialized countries to understand the context and course of the AIDS epidemic in African countries, therefore, just as it is important for Africans to understand the epidemic in the West. Greater understanding of the diversity in the AIDS pandemic increases our ability to devise effective programs at home and to offer useful assistance to one another as

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each country responds to unique and universal challenges in order to live with AIDS.

ENDNOTES

It is a pleasure to express our gratitude to colleagues in the AIDS and Reproductive Health Network, in Muhimbili Medical Center, and in the Harvard School of Public Health for numerous discussions that have illuminated issues raised here. We thank Arthur Kleinman and Paul Farmer for instigating and supporting this effort, and Carrie J. Hunter, George Lwihula, Priscilla Reining, and David Hunter for their valuable comments and corrections on an earlier draft. Finally, we thank Julie Rioux and Linda Markarian for their indefatigable assistance in the preparation of the manuscript.

[1]Epidemiology is the study of the distribution of an illness or other feature in a population, including description of the prevalence (number of cases of the illness divided by the number of people in the population at risk at a given time), incidence (number of new cases per unit of population per unit of time), and study of the host or environmental factors affecting these distributions.

[2]For review of this issue see René Sabatier, *Blaming Others: Prejudice, Race and Worldwide AIDS* (Washington, London, Paris: The Panos Institute, 1988).

[3]Many of the key papers chronicling this research effort have been collected in an edited volume, an invaluable resource for scientists working in institutions where recent scientific journals are often unavailable. See Dieter Koch-Weser and Hannelore Vanderschmidt, eds., *The Heterosexual Transmission of AIDS in Africa* (Cambridge: Abt Books, 1988).

[4]More than in any other region of the world, essential health, economic, and social statistics for African countries are based on extrapolations from sparse, often dated information. Population estimates for Africa in the late 1980s range from 500 million to 560 million. The latter figure was reported in K. C. Zachariah and My T. Vu, *World Population Projections, Short and Long Term Estimates* (Baltimore: Johns Hopkins University Press, 1988).

[5]R. P. Bernard, *AIDS-Feedback through 12/1988* (Geneva, Switzerland: Field Epidemiology and Liaison Office, 1988).

[6]B. Nkowane and J. Chin, "Surveillance and Reporting of the Acquired Immune Deficiency Syndrome (AIDS) in East and Central Africa," PS 5.5, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[7]World Health Organization, "A Global Response to AIDS," *Africa Report* (November-December 1988):13–16. For discussion, see Felix I. D. Konotney-Ahulu, "AIDS in Africa: Misinformation and Disinformation," *Lancet* (25 July, 1987):206–7; and *AIDS in the Third World*, 2d ed. (London: The Panos Institute, 1987).

[8]See findings cited in Table 2.

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[9]François Clavel et al., "Isolation of a New Human Retrovirus from West-African Patients with AIDS," *Science* 233 (1986):343–46; and Francis Barin et al., "Serological Evidence for a Virus Related to Simian T-lymphotropic Retrovirus III in Residents of West Africa," *Lancet* 2 (1985):1387–90.

[10]Phyllis J. Kanki et al., "Absence of Antibodies to HIV-2/HTLV-4 in Six Central African Nations," *AIDS Research and Human Retroviruses* 3 (3) (3 November 1987):317–22.

[11]Phyllis J. Kanki, "West African Human Retroviruses Related to HTLV-III," *AIDS* 1 (1987):141–45; and François Clavel, "HIV-2, The West African AIDS Virus," *AIDS* 1 (1987):135–40.

[12]*Toward Sustained Development in Sub-Saharan Africa* (Washington, D.C.: World Bank, 1984).

[13]See, e.g., Robert Caputo, "Uganda—Life Beyond Sorrow," *National Geographic* (April 1988):468–91.

[14]Peter Piot et al., "AIDS: An International Perspective," *Science* 239 (5 February 1988):573–79.

[15]Robert M. May, Roy M. Anderson, and Sally M . Blower, "The Epidemiology and Transmission Dynamics of HIV-AIDS," *Dædalus* 118 (2) (Spring 1989): 163–201. For discussion of the three global patterns observed internationally, see the article by June E. Osborn in this issue—"Public Health and the Politics of AIDS Prevention." Pattern I regions, defined by a concentration of HIV infection among homosexual men and intravenous drug users, is found in North America, western Europe, Australia, New Zealand, Brazil, and Mexico. Pattern II, defined by the predominance of heterosexual cases and transmission through contaminated blood transfusion, is found in most affected African countries and in some Caribbean countries.

[16]Thomas C. Quinn et al., "AIDS in Africa; An Epidemiologic Paradigm," *Science* 234 (21 November 1986):955–63; and Piot et al., "AIDS: An International Perspective."

[17]Ibid. For review, see Piot et al., "Heterosexual Transmission of HIV," *AIDS* 1(4) (December 1987):199–206; and Bosenge N'Galy and Robert W. Ryder, "Epidemiology of HIV Infection in Africa," *Journal of Acquired Immune Deficiency Syndromes* 1 (1988):551–58.

[18]Samuel I. Okware, "Epidemic of AIDS in Uganda," in G. Giraldo et al., eds., *AIDS and Associated Cancers in Africa* (Basel, Munchen, Paris, London: Krager, 1988); James W. Curran et al., "Epidemiology of HIV Infection and AIDS in the United States," *Science* 239 (1988):610–16.

[19]Transplacental transfer of maternal antibodies makes it difficult to distinguish infected infants from uninfected infants until maternal antibodies are lost. Research from the European MultiCentre Collaborative Study suggests that the customary twelve-month follow-up period may lead to slight overestimates of the proportion of HIV positive infants who are truly infected since some have been found to lose HIV antibodies at fifteen months. See the European MultiCentre Collaborative Study, "Mother-to-Child Transmission of HIV Infection," *Lancet*

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2 (5 November 1988):1039–42, and "Vertical Transmission of HIV," *Lancet* 2 (5 November 1988):1057–58.

[20]Wendy Goethel, "Problems of HIV Infection for Women in Africa," *IPPF Medical Bulletin* 22 (3) (1988):1–4.

[21]For review, see James Chin, Gopal Sankaran, and Jonathan Mann, "Mother-to-Infant Transmission of HIV: An Increasing Global Problem," *Maternal and Child Care in Developing Countries*, ed. E. Kessel and A. K. Awan (Thun, Switzerland: O. H. Publishers, 1988).

[22]Piot et al., "AIDS: An International Perspective."

[23]Studies reviewed in Quinn et al.; Robert J. Biggar, "The AIDS Problem in Africa," *Lancet* (11 January 1986):79–82.

[24]Jonathan M. Mann et al., "The International Epidemiology of Aids," *Scientific American* (October 1988):82–89; and Curran et al.

[25]Peter Piot et al., "Acquired Immunodeficiency Syndrome in a Heterosexual Population in Zaire," *Lancet* (14 July 1984):65–69; Quinn et al.; and Nancy Padian, "Heterosexual Transmission of Acquired Immunodeficiency Syndrome: International Perspectives and National Projections," *Review of Infectious Diseases* 9 (5) (September-October 1987):947–60.

[26]Joan Kriess et al., "AIDS Virus Infection in Nairobi Prostitutes, Spread of the Epidemic to East Africa," *New England Journal of Medicine* 314 (7) (13 February 1986):414–18; J. Killewo et al., "Risk Factors for HIV Infection in a Population Base Survey in Tanzania," abstract #5620, Fourth International Conference on AIDS, Stockholm, Sweden, 12–16 June 1988; and M. Merlin et al., "Epidemiology of HIV-1 Infection Among Randomized Representative Central African Populations," *Annales Institute Pasteur/Virology* 138 (1987):503–20. For review, see Piot et al., "Heterosexual Transmission of HIV"; Peter Piot and M. Mann, "Bidirectional Heterosexual Transmission of Human Immunodeficiency Virus (HIV)," *Annales Institute Pasteur/Virology* 138 (1987):12–32, reprinted in Kock-Weser and Vanderschmidt, 119–25; and Jonathan M. Mann et al., "HIV Infection and Associated Risk Factors in Female Prostitutes in Kinshasa, Zaire," *AIDS* 4 (2) (1988):249–54.

[27]See, for example, Peter Piot and Marie Laga, "Genital Ulcers, Other Sexually Transmitted Diseases, and the Sexual Transmission of HIV," *British Medical Journal* 298 (11 March 1989):623–24; Quinn et al.; Ruth M. Greenblatt et al., "Genital Ulceration as a Risk Factor for Human Immunodeficiency Virus Infection," *AIDS* 2 (1988):47–50; and Mann et al.

[28]See, for example, D. Serwadda et al., "Slim Disease: A New Disease in Uganda and its Association with HTLV-III Infection," *Lancet* (19 October 1985):849–52. See, for example, N'Galy and Ryder.

[29]This and other studies suggest that men who are uncircumcised are at slightly higher risk of contracting HIV infection than are circumcised men. See J. Neil Simonsen, "Human Immunodeficiency Virus Infection Among Men with Sexually Transmitted Diseases: Experience From a Center in Africa," *New England Journal of Medicine* 26 (2) (13 January 1989):288.

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[30]See, for example, Robert J. Biggar; N'Galy and Ryder; Piot et al., "AIDS: An International Perspective"; Daniel B. Hrdy, "Cultural Practices Contributing to the Transmission of Human Immunodeficiency Virus in Africa," *Reviews of Infectious Diseases* 9 (6) (November-December 1987):1109–19; and Bernard Guyer and Darryll Candy, "Injectable Antimalarial Therapy in Tropical Africa; Iatrogenic Disease and Wasted Medical Resources," *Transactions of the Royal Society of Tropical Medicine and Hygiene* 73 (2) (1979):230–32.

[31]See, for example, Piot et al., "AIDS: An International Perspective"; Alan Greenberg et al., "The Association between Malaria, Blood Transfusions and HIV Seropositivity in a Pediatric Population in Kinshasa, Zaire," *Journal of the American Medical Association* 259 (4) (22–29 January 1988): 545–49.

[32]J. K. G. Mati, "Infertility in Africa: Magnitude, Major Causes and Approaches to Management," *Journal of Obstetrics and Gynecology of Eastern Central Africa* 5 (65) (1986):65–69; and John C. Caldwell and Pat Caldwell, "The Demographic Evidence for the Incidence and Cause of Abnormally Low Fertility in Tropical Africa," in *The World Health Statistics Quarterly* 36 (1) (Geneva: World Health Organization, 1983).

[33]V. R. Attili et al., *Medical Journal of Zambia* (January 1983):19–21, cited in Panos Institute, *Aids in the Third World*, p.20.

[34]S. A. Dielly et al., "Relationship between Infection With HIV and Other Sexually Transmitted Diseases among Patients Attending a Referral Clinic for Sexually Transmitted Diseases in Tanzania," abstract W 5.1, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[35]See World Health Organization, "A Global Response to AIDS"; R. Colebunders et al., "HIV Infection in Patients with Tuberculosis in Kinshasa, Zaire," abstract TP 46, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988; P. Eriki, "Whither Tuberculosis? Uganda's Experience," abstract TP 32, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988; J. Mann et al., "Association between HTLV-III/LAV Infection and Tuberculosis in Zaire," *Journal of the American Medical Association* 256 (July 1986):346–48.

[36]We are grateful to Drs. Mary Halloran, Jody Heymann, and Claudio Struchiner for pointing out this important issue.

[37]World Health Organization, *Evaluation of the Strategy for Health for All by the Year 2000, Africa Region*, vol. 2 (Brazzaville: World Health Organization, 1987):21.

[38]See, for example, Robert I. Colebunders et al., "Evaluation of a Clinical Case Definition of AIDS in African Children," *AIDS* 1 (1987):151–53; C. S. Mgone et al., "Prevalence of HIV Infection and Symptomatology of AIDS in Severely Malnourished Children," abstract W 3.5, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[39]In a study in northern Zaire, for example, only five of ten hospitalized patients who met the clinical criteria for a diagnosis for AIDS were HIV seropositive. See Nzila

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Nzilambi et al., "The Prevalence of Infection with Human Immunodeficiency Virus Over a Ten-year Period in Rural Zaire," *New England Journal of Medicine* 318 (5) (4 February 1988):276–79. See also, for example, K. M. DeCock et al., "HIV-1 and HIV-2 Infection in Abidjan, Côte d'Ivoire," abstract W 16, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988. On the revised clinical case definition, see World Health Organization, "Acquired Immunodeficiency Syndrome (AIDS)," *Weekly Epidemiology Record* 61 (1986):69–73. When applied only to cases where other causes of immune suppression have been ruled out, specificity of 85 to 90 percent is achieved (see Colebunders et al., "Evaluation of a Clinical Case"). However, the revised definition was formulated expressly because the staff and equipment required to rule out cancer and other immunosuppressive conditions is available in so few hospitals and clinics.

[40]C. E. Anyiwo, "Clinical Case Definition in Developing Countries," *WHO Report* 3 (1988):6.

[41]Piot et al., "Heterosexual Transmission of HIV."

[42]World Health Organization, "A Global Response."

[43]World Bank, *Toward Sustained Development*; "African International Efforts Fail to Halt Economic Slide," *Africa Recovery* 2 (4) (1988):22–24.

[44]Ibid.; Michael Meegan and James McCormick, "Prevention of Disease in the Poor World," *Lancet* (16 July 1988):152–53.

[45]Charles N. Myers and Albert E. Henn, "Public Health: The Potential Impact of AIDS in Africa," in Robert I. Rotenberg, eds., *Africa in the 1990's and Beyond, U.S. Policy Opportunities and Choices* (Reference Publications, The World Peace Foundation, 1988):139–67.

[46]R. M. Anderson, R. M. May, and A. R. McLean, "Possible Demographic Consequences of AIDS in Developing Countries," *Nature* 332 (17 March 1988):228–34.

[47]John Bongaarts, *Modeling the Spread of HIV and the Demographic Impact of AIDS in Africa* (New York: The Population Council, October 1988).

[48]For discussion, see May, Anderson, and Blower.

[49]Myers and Henn have argued that because of the present age structure and the concentration of HIV in urban areas in a minority of countries, only 6 percent of the population of Africa is presently at risk of HIV infection. See Charles Myers and Albert Henn, "Public Health."

[50]John Bongaarts, *Modeling the Spread of HIV and the Demographic Impact of AIDS in Africa* (New York: The Population Council, October 1988).

[51]For example, M. Melbye et al., "Evidence for Heterosexual Transmission and Clinical Manifestations of Human Immunodeficiency Virus Infection and Related Conditions in Lusaka, Zambia," *Lancet* (15 November 1986):1113–15. But see, for example, N'Galy and Ryder, "Epidemiology of HIV Infection," and Piot et al., "Acquired Immunodeficiency Syndrome."

[52]Discussion of these issues is beyond the scope of this paper, but given differences in access to STD and AIDS prevention resources, among other things, cross-

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sectional comparisons showing higher HIV prevalence in higher income groups are not a good indicator of the future social distribution of HIV. On lack of association with ethnicity see, for example, Piot et al., "Acquired Immunodeficiency Syndrome"; Mann et al., "Association Between HTLV-III/LAV." On high and/or low income, see Melbye et al., "Evidence of Heterosexual Transmission"; and N'Galy et al.

[53]Brooke Grundfest Schoef et al., "AIDS and Society in Central Africa: A View from Zaire," in Norman Miller and Richard C. Rockwell, eds., *AIDS in Africa: The Social and Policy Impact* (Lewiston and Queenston: Edwin Mellen Press, 1988):211–35.

[54]Francis Paine Conant, "Social Consequences of AIDS: Implications for East Africa and the Eastern United States," in Richard A. Berk, ed., *The Social Impact of AIDS* (Cambridge: Abt Books, 1988):133–43.

[55]J. Judgren, 1974, cited in Marja-Liisa Swantz, "Woman as Producer and Provider in Bukoba District," in M. L. Swantz, *Women in Development: A Creative Role Denied?* (New York: St. Martin's Press, 1985):48–95.

[56]We are grateful to Dr. Priscilla Reining for providing much of the ethnographic information reported here and for discussions with her and with Dr. George Lwihula of Muhimbili Medical Center, Dar es Salaam, which brought many of the issues into focus. See Priscilla Reining, "Social Factors and Food Production in an East African Peasant Society: The Haya," in S. M. Peter, ed., *African Food Production Systems* (Baltimore: MacLoughlin, 1970).

[57]J. W. Whiting, V. K. Burbank, and M. S. Ratner, "The Duration of Maidenhood Across Cultures," in B. A. Hamburg and J. B. Lancaster, eds., *School Age Pregnancy and Parenthood* (New York: Aldine de Gruyler, 1986).

[58]Nici Nelson, "Selling her Kiosk: Kikuyu Notions of Sexuality and Sex for Sale in Mathare Valley, Kenya," in Pat Caplan, ed., *The Cultural Construction of Sexuality* (London and New York: Tavistock Publications, 1988), 217–37; and Suzanne G. Frayser, *Varieties of Sexual Experience, An Anthropological Perspective on Human Sexuality* (New Haven: HRAF Press, 1985).

[59]Gwen J. Broude, "Extramarital Sex Norms in Cross-Cultural Perspective," *Behavior Science Research* 15 (3) (1980):181–218; and Suzanne G. Frayser, *Varieties of Sexual Experience*, pp. 323–59.

[60]Marja-Liisa Swantz, "Woman as Producer and Provider in Bukoba District."

[61]Priscilla Reining, "Social Factors and Food Production."

[62]Fred S. Mhalu et al., "Some Aspects on the Epidemiology of AIDS and Infections with the Human Immunodeficiency Virus in the United Republic of Tanzania," in G. Giraldo et al., eds., *AIDS and Associated Cancers in Africa* (Basel, Munchen, Paris, London: Krager, 1988).

[63]Gernard I. Msamanga and K. J. Pallangyo, "Characterization of Tanzanian Outpatients Presenting with Sexually Transmitted Diseases," *East African Medical Journal* 64 (1) (1987):30–36.

[64]Mhalu et al., "Some Aspects on the Epidemiology of AIDS"; and Serwadda et al., "Slim Disease."

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[65]George Lwihula, personal communication, 1989.

[66]Mhalu et al., "Some Aspects on the Epidemiology of AIDS."

[67]J. Killewo et al., "The Epidemiology of HIV-1 Infection in the Kagera Region of Tanzania," abstract PS 5.6, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[68]J. Killewo et al., "Risk Factors for HIV Infection."

[69]F. S. Mhalu et al., "Rising Prevalence of HIV Infection and General Attitude to Condom Utilization among Restaurant and Bar Workers in Dar es Salaam City," abstract PS 7.3, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[70]Richard Parker, "Acquired Immunodeficiency Syndrome in Urban Brazil," *Medical Anthropology Quarterly* 1 (2) (June 1987):155–75.

[71]Jonathan M. Mann et al., "Surveillance for AIDS in a Central African City," *Journal of the American Medical Association* 255 (23) (20 June 1986):3255–59.

[72]Early on Klovdahl proposed analysis of HIV dissemination using a network model in order to take such patterns into account. See Alden S. Klovdahl, "Social Networks and the Spread of Infectious Diseases: The AIDS Example," *Social Science Medicine* 21 (11) (1985):1203–16; and Priscilla Reining, "How Rules for Dyads and Groups are Being Used for Research on AIDS," paper presented at workshop, Cultural Factors in AIDS Overseas, American Association for the Advancement of Science Annual Meeting, Boston, February 1988.

[73]Bill Freund, *The Making of Contemporary Africa* (Bloomington: Indiana University Press, 1985).

[74]See, for example, David Mechanic, *Medical Sociology* (New York: The Free Press, 1968); P. Conrad and R. Kern, eds., *The Sociology of Health and Illness: Critical Perspectives* (New York: St. Martin's Press, 1985); Lisa F. Berkman, "Physical Health and Social Environment: A Social Epidemiological Perspective," in L. Eisenberg and A. Kleinman, eds., *The Relevance of Social Science for Medicine* (Boston: D. Reidel, 1981):51–75.

[75]For discussion of medical pluralism in urban and rural areas, see, for example, John M. Janzen, *The Quest for Therapy, Medical Pluralism in Lower Zaire* (Berkeley: University of California Press, 1988); and Charles M. Good, *Ethnomedical Systems in Africa* (New York: Guilford Press, 1987).

[76]Charles Good, "Traditional Healers and AIDS Management," in Norman Miller and Richard C. Rockwell, eds., *AIDS in Africa: The Social and Policy Impact* (Lewiston and Queenston: Edwin Mellen Press, 1988):97–113.

[77]For perspectives on medical pluralism in industrialized as well as developing country settings, see Charles Leslie, "Medical Pluralism in World Perspective," *Social Science and Medicine* 14 B (4) (November 1980):191–95; and Margaret Lock, *East Asian Medicine in Urban Japan: Varieties of Medical Experience* (Berkeley: University of California Press, 1980).

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[80]See Nelson, "Selling her Kiosk"; Gayle Rubin, "The Traffic in Women: Notes on the 'Political Economy' of Sex," in Rayna R. Reiter, ed., *Toward an Anthropology of Women* (New York: Monthly Review Press, 1975):157–210; and Jean La Fontaine, "Free Women of Kinshasa: Prostitution in a City of Zaire," in *Choice and Change* (Atlantic Highlands, N.J.: Humanities Press, 1974).

[81]Brooke Grundfest Schoepf, "Women, AIDS and Economic Crisis in Central Africa," *Canadian Journal of African Studies* (October 1987).

[82]Based on figures for annual incidence of malaria in World Health Organization, *Evaluation of the Strategy for Health for All by the Year 2000*, vol. 1 (Geneva: World Health Organization, 1987).

[83]Having averaged 6.1 percent per year between 1970 and 1982 according to the World Bank in 1984, rates of urbanization in African countries far exceed those in other parts of the developing world. On the impact of violence and warfare, see Dennis A. Ityavyar and Leo O. Ogba, "Violence, Conflict and Health in Africa," *Social Sciences and Medicine* 28 (7) (1989):649–57.

[84]For example, Bill Freund, *The Making of Contemporary Africa*.

[85]Femi Soyinka, "Where AIDS and HIV Infection Prevalence is Low," abstract PS 5.2, Third International Conference on AIDS and Associated Cancers in Africa, Arusha and Tanzania, 14–16 September 1988.

[86]World Health Organization, eds., *AIDS Prevention and Control* (Oxford: Pergamon Press, 1988).

[87]World Health Organization, "A Global Response."

[88]Ibid.

[89]René Sabatier, *Blaming Others*.

[90]World Health Organization, *Statement for the Consultation of Breast-Feeding and Breast Milk and Human Immunodeficiency Virus (HIV)* (Geneva: World Health Organization, 1988).

[91]See, for example, E. Maxine Ankrah and Charles B. Rwabukwali, *School Health Education: Implications for AIDS Control* (Uganda: UNICEF, 1987); and interview with Drs. Esther Gwan and Jenny Almeida, "Methods for Starting Discussion with School-age Cameroon Teenagers," *AIDS Action* 2 (1988):2–3.

[92]Roger V. Short, "Condoms," lecture presented at the Harvard School of Public Health, Boston, 6 April 1989.

[93]The abstracts of the First International Symposium on Education and Communication about AIDS, Ixtapa, Mexico, 16–20 October 1988, contain an impressive array of reports.

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[94]For example, socioeconomic and urban-rural differences in access to health information, services, and supplies; age, sex and ethnic differences in literacy; and keenly felt barriers to cross-sex and cross-generational communication about sexual behavior or symptoms of sexually transmitted disease.

[95]Harvey V. Fineberg, "Education to Prevent AIDS, Prospects and Obstacles," *Science* 239 (5 February 1988):592–96.

[96]Robert Hornik and Susan McCombie, "General AIDS Education: Cross-National Evidence of Effects," paper presented at the First International Symposium on Education and Communication on AIDS, Ixtapa, Mexico, 16–20 October 1988.

[97]Noerine Kaleba, paper presented at the First International Symposium on Education and Communication on AIDS, Ixtapa, Mexico, 16–20 October 1988.

[98]Schoepf et al., "AIDS and Society."

[99]E. N. Ngugi et al., "Prevention of Transmission of Human Immunodeficiency Virus in Africa: Effectiveness of Condom Promotion and Health Education Among Prostitutes," *Lancet* (15 October 1988):887–90; Rukarangira wa Nkera (work in progress); Peter Lamptey et al., "A Model Program to Reduce HIV Infection among Prostitutes in Africa," paper presented at the Fourth International Conference on AIDS, Stockholm, 5–9 June 1988, abstract 5149.

[100]In reality, the United States ranks very low among industrialized countries in the proportion of national GNP invested in foreign assistance. In 1984, when this proportion was more than 1 percent in Scandinavian countries, 0.77 percent in France, and 0.35 percent in Japan, the U.S. investment in foreign aid amounted to just 0.24 percent of the GNP—a level only slightly higher than that of the Soviet bloc countries. See the Joint Ministerial Committee of the Boards of Governors of the World Bank and the International Monetary Fund on the Transfer of Real Resources to Developing Countries (Development Committee), *Aid for Development: The Key Issues* (Washington, D.C.: Joint Ministerial Committee, 1984).

[101]Lincoln C. Chen, "The AIDS Pandemic: An Internationalist Approach to Disease Control," *Dædalus* 116 (2) (Spring 1987):181–95.

[102]Institute of Medicine, *Confronting AIDS, Update 1988* (Washington, D.C.: National Academy of Sciences, 1988).

[103]Nicholas A. Christakis, "The Ethical Design of an AIDS Vaccine Trial in Africa," *Hastings Center Report* (June-July 1988):31—37.

[104]Nicholas A. Christakis, "Responding to a Pandemic: International Interests in AIDS Control," *Dædalus* 118 (2) (Spring 1989):113–34.

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Harlon L. Dalton

AIDS in Blackface

MY AMBITION IN THE PAGES THAT FOLLOW is to account for why we African-Americans have been reluctant to "own" the AIDS epidemic, to acknowledge the devastating toll it is taking on our communities,[1] and to take responsibility for altering its course. By the end, I hope to convince you that what may appear to the uninitiated to be a crazy, self-defeating refusal to stand up and be counted is in fact sane, sensible, and determinedly self-protective. The black community's impulse to distance itself from the epidemic is less a response to AIDS, the medical phenomenon, than a reaction to the myriad social issues that surround the disease and give it its meaning. More fundamentally, it is the predictable outgrowth of the problematic relationship between the black community and the larger society, a relationship characterized by domination and subordination, mutual fear and mutual disrespect, a sense of otherness and a pervasive neglect that rarely feels benign.

If I am right, then there is a profound need to reorient the public health enterprise so that it can succeed in a multicultural society. Public health officials cannot simply wander uptown (or wherever the local black ghetto is situated), their expertise in one hand, their goodwill in the other, and expect to slay the disease dragon. They must first discern just who this particular public is and how it sees itself in relation to them. How does the black community see its own

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health needs, and how do they stack up against its other concerns? And, not least, just what has been the black community's prior experience in dealing with government do-gooders?

Answering these questions is not an impossible task, even in the midst of an epidemic. Consider, for example, the extent to which the relationship between the white gay community[2] and the public health establishment changed in the mid-1980s. Much has been written about the latter's failure to intervene in a timely and sensitive way early on, when the AIDS epidemic might have been successfully contained.[3] I do not quarrel with the explanations usually proffered for this failure—the health establishment's inability to identify with or care about the gay men who were viewed as the disease's principal targets, bureaucratic ineptitude and infighting, and an administration in Washington mindlessly committed to reducing social spending no matter what. I do, however, want to highlight an additional factor, the fact that initially most public health officials approached AIDS as solely a biomedical phenomenon and exhibited little comprehension of the many ways in which culture, politics, and disease intersect. Thus they failed to realize how much freight would attach to their well-intentioned attempts to safeguard the public's health and did not anticipate that both the gay community and the larger society would react in ways reflective of the social distance between the two.

The moment of truth arrived shortly after the Food and Drug Administration approved the first HIV antibody test for the screening of the nation's blood supply. Many health officials advocated that the test be used diagnostically as well, to determine whether persons in so-called high-risk groups had been exposed to the virus. The officials were surprised to discover that most gay organizations and AIDS support organizations took the opposite view and strongly recommended that gay men, including those who had engaged in high-risk activity, *not* take the test.[4]

At first, the public health establishment saw this resistance as misguided, irresponsible, and self-destructive. In fairly short order, however (thanks largely to the efforts of "bridge" people who served, in effect, as bicultural interpreters), key officials began to see past the bare fact that their recommendations were being opposed, to the concerns underlying the gay community's opposition: that the test was not sufficiently accurate to be used for diagnostic purposes; that testing would produce needless mental anguish for many; that

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persons seeking the test might thereby open themselves to criminal liability by admitting to having engaged in sodomy or the use of illicit drugs; that testing would facilitate the quarantining of persons who tested positive; that absent strict confidentiality, testing would lead (at least for seropositives) to the loss of insurance, employment, and housing, and to social isolation and vilification as well. These concerns, the officials realized, were as much the lived reality of AIDS as helper-T cells and transmission routes.

It became apparent that to reach the gay community, public health officials had to learn to view the epidemic from the perspective of the gay community. Consequently, today even the most control-minded health officials take care to involve the gay community in decision making and emphasize the need for a high degree of test accuracy, for strict confidentiality, and for enhanced laws against discrimination.[5] The moral of this story is plain. The public health establishment *can* take account of community differences if it has to. It *can* take account of the sociopolitical contexts in which it operates. It *can*, if pressed, recognize that its targets are, in an important sense, its teachers. My hope is that the failure of New York's needle-exchange program, together with other failures to reach the black community, will, like the white gay opposition to testing in the mid-1980s, provoke thoughtful reconsideration of how the public health enterprise should operate in a society deeply divided along racial lines.

I have arrived at the conclusions in this essay in much the same way a reporter, or perhaps a biographer, would. Rather than engage in rigorous empirical research, I have relied on my store of impressions formed over several years of communicating about AIDS with the black community and, more important, listening to concerns voiced outside that community. The comparison to reporting and biography is less than perfect inasmuch as I do not claim to be neutral. I do not pretend to be solely a channel for the experiences and expressions of others. On the contrary, as a member of the black community I have personally experienced most of the sentiments and dynamics about which I report, and like human beings in general, tend to view others' experience through the prism of my own. My hope is that the texture and depth of the result will more than offset any distortions.

My approach rests on two assumptions—that an African-American subculture exists (marked by shared sentiments, sensibilities, experiences, and history) and that I am sufficiently linked to it

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(by virtue of upbringing, kinship ties, and spirit) to be qualified to interpret it.

The first proposition is, I should think, relatively unproblematic so long as we remain near the subculture's core and resist the temptation to specify its precise contours. As for the second proposition, you are, I am afraid, going to have to trust me, at least provisionally. The true test of my entitlement to speak about (not for) the black community will be whether my words resonate for the majority of its members (and for the small set of others who know it well).

On occasion I will take the liberty of treating you, dear reader, as a stand-in for white America. That is to say, I will speak directly to *it* through *you*. My goal in so doing is not to artificially divide (though that is certainly a risk I take), but rather to speak in a way that captures the timbre as well as the pitch of the community sentiments I seek to convey.

THE IMPACT OF AIDS

Unquestionably, AIDS has hit the black community hard. We are losing our sons and daughters at an alarming rate. Twenty-five percent of all persons with AIDS in the United States are African-American.[6] Among the newly diagnosed, the figure exceeds 36 percent.[7] In many Eastern cities, blacks and Latinos constitute a majority of the AIDS cases.[8] In New York City, where AIDS is the number one killer of women between the ages of twenty-five and thirty-four,[9] black women, with their Latina sisters, account for 84 percent of the adult female AIDS cases.[10] Nine out of ten children with AIDS in New York City are black or Latino.[11] In the Bronx one baby in forty-three is born infected.[12] Across the board, black people are disproportionately represented. Thus, even among gay and bisexual men and intravenous drug users, blacks are more likely to be infected than are their white counterparts.[13] On average, black persons with AIDS (PWAs) are sicker at time of diagnosis than white PWAs and die nearly five times as rapidly.[14]

Notwithstanding this bleak picture, public health officials and AIDS organizations around the country have been frustrated in their efforts to organize the black community to deal with AIDS.[15] While the vast majority of such people and organizations are predominantly white, even black and Latino officials and activists have run into

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more than their fair share of walls.[16] Resistance within the community ranges from the simple refusal to acknowledge that AIDS is a problem for black people (an increasingly difficult position to maintain in the face of the overwhelming numbers) to the rejection of programs designed to stem the transmission of HIV. In between these extremes, our leaders, however defined, seem to run away from the issue of AIDS. They talk about it as little as possible and even more rarely involve themselves in efforts to develop constructive solutions.[17]

Perhaps the most dramatic example of the black community's resistance to AIDS intervention involves New York City's pilot needle-exchange program. The goal of the program is to test whether addicts will, if given a chance, exchange used needles for clean ones, and if so, whether that step will appreciably lower the incidence of HIV infection in the addict population. Originally designed to operate in neighborhoods where drug abuse is prevalent, the program was located instead, thanks to pressure from black and Latino community leaders, in a downtown government office building, far away (geographically and otherwise) from its target population. This concession of city officials (a move that, in the view of most observers, severely compromised the program's prospects for success) did not, however, dampen community opposition. On the contrary, word of the program's grand opening "ignited," in the words of one reporter.[18]

Typical of the reaction was Harlem city council member Hilton B. Clark, who characterized the program as a "genocidal campaign."[19] A key opponent was New York's police commissioner, Benjamin Ward, who explained that as a black person, he had "a particular sensitivity to doctors conducting experiments, and they too frequently seem to be conducted against blacks." One month after needle exchange began, the New York City Council, led by its black and Hispanic caucus, urged the health commissioner to cancel the program. In commenting on the nonbinding resolution, which passed on a vote of 31–0, caucus chair Enoch Williams explained that "the city is sending the wrong message when it distributes free needles to drug addicts while we are trying to convince our children to say no to drugs."[20]

City officials were not the only ones to join the chorus. For example, Rev. Reginald Williams of the Addicts Rehabilitation

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Center in East Harlem promised that "there will never be a needle-exchange program here. I think the communities and neighborhoods would rise up in opposition. They tell me this is what we must try. . . . Why must we again be the guinea pigs in this genocidal mentality?"[21] To the surprise of many, the needle-exchange program was even opposed by the likes of Dr. Beny J. Primm, a highly respected leader in the field of substance abuse and a belated addition to former President Reagan's AIDS Commission. Primm took issue with the claim that needle exchange would lower the incidence of HIV transmission and, as an alternative, pushed for a more rational system of assigning addicts to available treatment program openings.[22] There were, of course, some blacks and Latinos who lined up in favor of the program, most notably the Brooklyn-based Association for Drug Abuse Prevention and Treatment (ADAPT), led by Yolanda Serrano.[23] For the most part, however, the community response was exceedingly negative.

THE RELUCTANCE TO "OWN" AIDS

Already, a set of stock explanations for this reluctance has emerged. We are told that for too long the media have inaccurately portrayed AIDS as a disease that almost exclusively afflicts white gay men,[24] that for too long public health officials have failed to use media appropriate to the black community,[25] and that the black church has stood in the way of effective AIDS education because of its opposition on moral grounds to homosexuality and drug use.[26] While valid to a point, these explanations have, in my opinion, been very much overblown. First, the mass media are scarcely the only avenues of communication in the black community (a point made by some of the same people who seek to pin the misrepresentation tail on the media).[27] Moreover, we have long since learned to view the media with suspicion and to discount their distortions when our own experiences contradict them. Second, even though the public health establishment has relied on media not well suited to reaching the black population (too many pamphlets and not enough radio spots, for example), by and large health officials have used the same media that arguably have succeeded at presenting a distorted picture of who has AIDS.

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As for the third stock explanation, it does a disservice, in my view, to the black church. It is, of course, true that much of the church is doctrinally fundamentalist and socially conservative. These characteristics, however, are constraints not so much on what can be done in the realm of social action as on how to do it. In practice, the church has proved adaptable, pragmatic, and even crafty when need be. To paraphrase former President Nixon, if you want to understand the black church, watch what it does, not what it says. Time and again, the church has demonstrated its awareness of the variability of human existence and the fragility of the soul under siege. Time and again, the church has been responsive to the needs, spiritual and nonspiritual, of the community. The civil-rights movement of the 1950s and 1960s is simply the most dramatic example in recent memory.

What else, then, accounts for the black community's reluctance to grapple with AIDS? I have isolated five overlapping factors that I think explain a great deal. The first is that many African-Americans are reluctant to acknowledge our association with AIDS so long as the larger society seems bent on blaming us as a race for its origin and initial spread. Second, the deep-seated suspicion and mistrust many of us feel whenever whites express a sudden interest in our well-being hampers our progress in dealing with AIDS. Third, the pathology of our own homophobia hobbles us. Fourth, the uniquely problematic relationship we as a community have to the phenomenon of drug abuse complicates our dealings with AIDS. And fifth, many in the black community have difficulty transcending the deep resentment we feel at being dictated to once again.

Blame

Early on in the AIDS epidemic, and continuing for some time, scientists, the press, and the public seemed curiously fixated on the origins of the virus associated with AIDS. From the perspective of the black community, interest in HIV's possible African roots seemed insatiable. Article after article appeared, recirculating identical hypotheses. The discovery of a similar virus in the African green monkey stirred the pot and prompted endless speculation about how it might have traveled from an "animal reservoir" into the human species. When pressed to explain why so much time and energy was being devoted to so marginal a concern, white people usually

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responded that determining where the virus originated might lead to the discovery of ways to slow it down or eliminate it altogether. Perhaps. Black folks, however, offered a different explanation. We understood in our bones that with origin comes blame. The singling out of Haitians as a so-called risk group simply confirmed our worst fears.

Although the society's fixation with the origin of AIDS has faded and Haitians are no longer officially viewed as synonymous with AIDS, for us the memory dies hard. Our exasperation and sometimes rage lingers just below the surface. Were I to go out tomorrow and speak about AIDS to a black audience anywhere in this country, I guarantee you that once the discussion got going, someone would ask about the disease's origins. The question "Is it true that it started in Africa?" would quickly become "Why do they keep trying to pin it on Africa?" "Why do they keep trying to pin it on us?" and eventually I would be asked the clincher: "What are they trying to say we *did* with that monkey?"

More than insult and affront are at issue here. So long as we African-Americans continue to worry that any hint of connection with AIDS will be turned against us, we will remain leery of accepting responsibility for its impact on our community.

Suspicion and Mistrust

It is difficult to overemphasize the extent to which the black community, qua community, reflexively responds with suspicion and mistrust to what are perceived as "white" initiatives. Just as Jews admonish each other to "never forget," we do not wish to forget the bitter lessons we have been taught since being brought to these shores. Slavery, a subject one does not bring up in polite company, exists within our extended memory; my father used to sit around the dinner table with his grandmother, a former slave. Segregation was upon us only yesterday. Today we must deal with Ed Koch, David Duke, and political campaigns that showcase people like Willie Horton. Push just a little bit and you will tap into wellsprings of mistrust even in those of us who live much of our lives within the ambit of the larger society and negotiate it with apparent ease (though not without cost).

Frequently, our acute mistrust manifests itself as resistance, as sparring, as buying time until we are sure we are safe. The early

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"negotiations" with the black community regarding AIDS seem largely to have followed this pattern. Given enough time, we can together work our way out of the pattern by building up trust, but time is at a premium where AIDS is concerned. A second way out is for black people to reconceptualize AIDS as not something white America is insisting we deal with but rather as a set of issues we ourselves want to take on. In other words, in order to "own" AIDS even in part, we may need to own it outright.

Homophobia

A third reason the black community has been slow in responding to AIDS is that many of us do not want to be associated with what is widely perceived as a gay disease. More than once I have heard of black parents readily volunteering, so as to forestall even more embarrassing speculation, that their HIV-infected children are addicts. Homophobia is not, of course, unique to the black community, but it takes on a particular character within the context of African-American history and culture. Precious little has been written on the subject. Straight black authors tend to ignore the subject altogether. A notable exception is Bell Hooks, who deftly captures the complexity of black attitudes toward homosexuality and the imperfect connection between those attitudes and actual behavior.[28] Gay black writers seem to find it easier to train their fire on racism within the white gay community than on homophobia within the straight black community.[29] Recently a small but hardy band of academics has begun extensive research on the life experiences of black gay men and lesbians.[30] In time, this work will provide a rich base from which a fuller picture of the character and consequences of black homophobia can be drawn.

If we in the black community are to make progress coping with AIDS, we must deal simultaneously with our homophobia. As a first step, we must name the problem, map its contours, and develop an understanding of how it is detrimental to us as a community. I will not attempt to advance this enterprise very far here, in part because I am not sure that this essay is the best vehicle for doing so. I feel obliged, however, having flagged the issue, to at least say a bit more.

First, let me distinguish between homophobia that is directed at whites and homophobia that is internal to the black community. As we seek to understand the former, it will be difficult, I suspect, to

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disentangle it from an animus based on race. That is to say, gay whites who encounter hostility from blacks may be the target of antigay sentiment, antiwhite sentiment, or both. Even the originators of the hostility may not know where one motivation ends and the other begins. Moreover, racial prejudice and homophobia may well activate or reinforce each other. It stands to reason that someone who is viewed as an "other" along one dimension will more easily be viewed as an "other" along a second and third. Internal homophobia does not suffer this complication, but it scarcely lacks complexity. Like most aspects of the African-American subculture, its roots are dual. The black community has doubtless been influenced by the larger society's attitudes toward sexual minorities even as its historical experience has produced a distinctive set of attitudes and practices. I would like to focus briefly on the latter.

In the manner in which homosexuality is spoken about, the black community differs markedly from the larger society. In our denunciation of homosexuality and of persons thought to be gay, blacks (including closeted gays) tend to be much more open and pointed than whites.[31] Our verbal attacks seem tinged with cruelty and are usually delivered with an offhandedness that many white observers find unnerving. At the same time, there is, within the black community, an enormous gulf between talk and action, or for that matter, between talk and belief.[32] What we say and what we think, or do, need not be congruent. In fact, a cruel tongue is often used to hide a tender heart. Bell Hooks tells of a "straight black male in a California community who acknowledged that though he often made jokes poking fun at gays or expressing contempt as a means of bonding in group settings, in his private life he was a central support person for a gay sister." "Such contradictory behavior," she adds, "seems pervasive in black communities."[33]

On reflection, none of this is surprising. We, as a people, are given to verbal excesses, to hyperbole, to putdowns meant for sport rather than wounding. People of my generation and older grew up "playing the dozens," verbal horseplay that involved the most scandalous imaginable accusations about the families and acquaintances of the other participants. So long as you stayed within certain well-understood (albeit unwritten and unspoken) bounds of propriety, you could say vicious things without anybody thinking you really meant it. A similar dynamic attends verbal gay bashing. There is a

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common understanding of which nasty things are acceptable to say, and as long as one stays within the canon, one can claim an absence of malice.[34]

There is, however, a key difference. In the dozens, the participants stand on equal footing; typically they alternate between the role of the slanderer and the role of the slanderized. In addition, there is no necessary relationship between the calumnies heaped on an individual and those heaped on her or his real-life position. In fact, one of the unwritten rules is that you tread lightly around areas of true vulnerability.

In practice, black communities across the country have knowingly and sometimes fully embraced their gay members. But the price has been high. In exchange for inclusion, gay men and lesbians have agreed to remain under wraps, to downplay, if not hide, their sexual orientation, to provide their families and friends with "deniability." So long as they do not put the community to the test, they are welcome. It is all right if everybody knows as long as nobody tells.[35] That is more easily accomplished than you might imagine. For the most part, even the pillars of the black community are content to let its gay members be, and to live alongside them in mutual complicity. This is true even within the church. Indeed, it is a well-kept secret, or more precisely, it is well-denied knowledge, that gays are disproportionately represented within the ministry, including (and perhaps especially) the ministry of many of the more fundamental denominations.[36]

This complex relationship works most successfully when gay men and lesbians are willing to carry on appearances, to live, in effect, straight lives. Many gay black men seek the ultimate cover and become ostentatiously involved with women. One noteworthy consequence of this phenomenon is that their female sexual partners may unknowingly be exposed to an increased risk of HIV infection.[37]

What accounts for the way in which the black community has approached homosexuality—boisterous homophobic talk, tacit acceptance in practice, and a broad-based conspiracy of silence? I have a theory (and it is no more than that) that within the black community, internal homophobia has less to do with regulating sexual desire and affectional ties than with policing relations between the sexes. In this view, gay black men and lesbians are made to suffer because they are out of sync with a powerful cultural impulse to

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weaken black women and strengthen black men. They are, in a sense, caught in a sociocultural cross fire over which they have little control.

Among the many horrors of slavery is the havoc it wreaked on relations between black men and women. Slave couples were not allowed to form stable bonds, and those relationships that did develop were burdened in ways painful to recount. Men were torn away from their families, women were subjected to the slavemasters' bidding, and both were, on occasion, bred like animals. As a result, men were unable to provide for, much less protect, "their" women and women were unable to rely on their men. This emasculation of black men (when measured against traditional gender role expectations and concepts of male prerogative) bode ill for male-female relations in the postslavery era in the absence of a fundamental redefinition of gender. The near century of Jim Crow that followed—legalized discrimination backed up and surrounded by powerfully disintegrative social forces—simply added to the strain. Black people in general, and black men in particular, were "kept in their place," routinely excluded from places that would bring them honor and respect or that would allow them to serve as family providers. While women could usually find employment as domestics, black men frequently drifted and did not, could not, come close to pulling their own weight.

For me, this reality is best captured by something that happened on the old Art Linkletter show during the 1950s, I believe. The show included a segment entitled "Kids Say the Darnedest Things," in which Linkletter interviewed children about whatever was on their minds. Somehow the word spread that on this particular day Linkletter would have a black kid on the show, a rare occurence. Like hundreds of thousands of other black folk, I eagerly tuned in and watched with fascination and horror as this little kid, who looked a lot like me, answered the question "What do you want to be when you grow up?" "I want to be a white man," he answered quickly and confidently. Linkletter gulped, paused, and then plunged ahead. "Why?" he asked. "Because," answered the kid, "my momma says that black men aren't worth shit!"

The network instantly broke for a commercial, and when the show returned, the little black kid had been whisked off the set, but no commercial break could stanch the psychic wound opened up in an entire community in that moment of childlike innocence. Black

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people talked about that show for months, amidst much handwringing and headshaking. Yet, despite the countless retellings and postmortems, the message implicit in the little boy's answer—that relations between black men and women had reached a parlous state—was never disputed.

What does this have to do with homophobia? My suspicion is that openly gay men and lesbians evoke hostility in part because they have come to symbolize the strong female and the weak male that slavery and Jim Crow produced. More than even the mother quoted on the Linkletter show, lesbians are seen as standing for the proposition that "black men aren't worth shit." More than even the "no account" men who figure prominently in the repertoire of female blues singers, gay men symbolize the abandonment of black women. Thus, in the black community homosexuality carries more baggage than in the larger society. To address it successfully, we may have to take on such larger issues as the social construction of gender and the nature of male-female relations.

Drug Abuse

A fourth impediment to our efforts to grapple with AIDS is the association of the disease with drug abuse. We as a community have a complex relationship with illicit drugs, a relationship that often paralyzes us. On the one hand, blacks are scared to even admit the dimensions of the problem for fear that we will all be treated as junkies and our culture viewed as pathological. On the other, we desperately want to find solutions. For us, drug abuse is a curse far worse than you can imagine. Addicts prey on our neighborhoods, sell drugs to our children, steal our possessions, and rob us of hope. We despise them. We despise them because they hurt us and because they *are* us. They are a constant reminder of how close we all are to the edge. And "they" are "us" literally as well as figuratively; they are our sons and daughters, our sisters and brothers. Can we possibly cast out the demons without casting out our own kin?

We know that white America cannot comprehend our dilemma. We know that you do not truly share our concerns. Your interest in drug abuse has always been episodic and shallow. During the 1960s, you focused briefly on the problem when you became convinced that most street crime and petty theft is drug related. Although some of you saw this opening as an opportunity to broaden the nation's

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commitment to drug prevention and treatment, most energy went into keeping white people from being victimized. Meanwhile, the plight of black victims "uptown" didn't even merit lip service. During the 1970s, drug abuse once again briefly took center stage as suburban high school students began to experiment and addicted GIs returned home from Viet Nam. Left in the shadows as usual was the civilian drug problem in our nation's inner cities.

Now, as the 1980s draw to a close, a combination of factors, including the rise of the social right, the highly visible fall of dozens of professional athletes, the intertwining of drug trafficking and foreign policy, the emergence of crack as the drug of choice among many communities, and, not least, AIDS, has made drug abuse a hotter social issue than at any time in recent history. Yet for all the *Sturm und Drang*, the white community has shown little concern that day by day, drugs are eating away at the heart and soul of the black community. When school children were gunned down by a maniac in Stockton, California, you furiously debated the wisdom of allowing private citizens to purchase semi-automatic weapons; at the same time, you appeared oblivious to the fact that every day in the inner city *our* children are being gunned down by such armaments in the never-ending struggle over drug turf and profits.

And so we find ourselves paralyzed, caught up in our own conflicting emotions—guilt, anger, shame, horror, fear, sympathy, aversion, affinity—and your uncertain commitment. We know that to deal with AIDS we must deal with drugs. If only we knew how.

Neocolonialism

Although most of my 1960s rhetoric is safely stored away in my mental attic, I was forced to resurrect this trusty old friend, for try as I might, I couldn't come up with a post-postmodern phrase that captures the one-sided relationship now existing between the black community and the larger society, a relationship built on power and control. When we want help, white America is nowhere to be found. When, however, *you* decide that we need help, you are there in a flash, solution in hand. You then seek to impose that solution on us, without seeking our views, hearing our experiences, or taking account of our needs and desires. We tell you that we fear genocide, and you quarrel with our use of the term. Then you try to turn our concerns back on us. "Don't you know," you ask us in an arch tone

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of voice, "that while you are standing on ceremony, thousands of the very people you say you care about are dying from AIDS?" Struggling to ignore the insulting implication that we are either profoundly retarded or monumentally callous, we respond, "Don't *you* know that they are already dying from drug overdoses, Uzis and AK-47s, joblessness, despair and societal indifference?" And, white America, you sigh and say, "What's one thing got to do with the other?" Then we sigh and wonder if you truly do not understand.

In the silence that follows, none of our real concerns gets voiced. Why can't *we* choose which of the many problems facing us to tackle first? Suppose we think that crack is more of a menace than AIDS? Are you willing to help us take on that one? Why do you want *us* to take all the risks? You say that making drug use safer (by giving away bleach or distributing clean needles) won't make it more attractive to our children or our neighbors' children? But what if you are wrong? What if as a result we have even more addicts to contend with? Will you be around to help us then, especially if the link between addiction and AIDS has been severed? Why do you offer addicts free needles but not free health care? Why do you show them how to clean their works but not how to clean up their lives? Why not provide immediate treatment for every addict who wants it? Why not provide us with job training so that our youth will have realistic alternatives to the street? Instead of asking us to accept on faith that we won't be abandoned and possibly worse off once you move on to a new issue, why not demonstrate your commitment by empowering us to carry on the struggle whether you are there or not?

WHERE TO FROM HERE?

Quite simply, we have to learn how to stop talking past each other. We have to figure out a way to communicate across the racial chasm. Our language is the same, but our frames of reference are so different. Admittedly, part of the blame for recent failures to connect rests with the black community. We have been so intent on trying to get your attention that we have occasionally forgotten why. We have been so busy expressing our fears that we have failed to express our hopes. We have been so focused on past fiascos that we have been unwilling to test whether this time we can work together. We have been afraid to say straight out what is on our minds. And too often when we

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speak, we do so cryptically, metaphorically, or in a code undecipherable by outsiders.

This concern brings me to the term *genocide*. Although I understand its appeal, I regret the use of the term in conversations about AIDS. My regret stems from the fact that *genocide* tends to be a conversation stopper, and I am desperately anxious for genuine conversation to begin. It is so hard to get past the term itself to the sentiments and experiences that animate its use. Yet those sentiments and experiences reveal a good deal about why efforts to organize the black community around AIDS have been disappointing, so let me take a run at it.

What do community leaders (and followers) mean when they accuse seemingly well-intentioned public health officials of engaging in genocide? Admittedly, the term is a useful club, the kind one uses to get a mule's attention. But that is not its sole function. After all, black folks use it meaningfully even when talking among ourselves. It speaks to us. It resonates. It is shorthand for a wide range of fears and expectations, all of which are backed up by shared experience.

In its strong form, the term *genocide* reflects the genuine suspicion of many that the AIDS virus was developed in a government laboratory for the express purpose of killing off the unwanted. This belief is helped along by HIV's curious affinity for those whom the larger society disdains. Lest you judge this a fringe concern, I must tell you that whenever I speak about AIDS to a grass-roots audience in a black neighborhood, at some point during the question-and-answer session someone invariably asks me whether I think AIDS was purposefully developed as a means of wiping out black people or, alternatively, whether black people are being used as guinea pigs to test this new form of biological warfare. Others in the room usually murmur their agreement with the statement within the question or wait expectantly for my answer.

Although I answer no, I understand full well where the question comes from and recognize that it must be heard against the backdrop of the larger society's historic disregard for the sanctity of black people's lives. We need not go back to slavery. There are examples aplenty within my lifetime, or that of my parents, of black people's lives being treated casually or worse. Take, for example, the infamous experiment at Tuskegee Institute in which the government purposefully exposed black men to syphilis so as to study the natural course

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of the disease. Although an effective treatment was developed mid-experiment, the men were never told about it and were never treated, lest the research be compromised.[38] Another well-documented example is the forced sterilization of women on welfare, many of whom were black or brown. In some states, the practice continued unabated into the 1970s.[39] The recent election of former Klansman David Duke to the Louisiana legislature suggests that this unlovely practice, a key element of his platform, has not altogether lost its appeal.[40] A third example, relatively recently come to light, is the FBI's attempt to pressure Dr. Martin Luther King, Jr., into committing suicide.[41] To these highly visible stories someone in every black audience can add dozens more, stories of people who found themselves the unwitting object of experimentation or the target of government persecution.

Two assumptions underlie the strong claim of genocide. The first is that the hostility of white America toward black America is so powerful, or the disregard so profound, that no depredation is unthinkable. This view is rooted in racial strife and feeds on the storehouse of sins visited upon blacks by whites. The second assumption is that under the right circumstances, the government is not above compromising the lives of innocent citizens. The grist for such a view is considerable. Time and again the government has demonstrated a willingness to jeopardize the lives of even its most favored in order to expand its knowledge or advance its policies. The purposeful exposure of American soldiers to radiation in the Nevada desert comes readily to mind.[42] For black people, the realization that even white skin does not protect one from being expendable is chilling indeed.

Less strongly, the term *genocide* reflects a widespread belief that the federal government willingly let AIDS spread as long as it was confined to populations that straight white America would rather do without. The grist for this view is provided by the government's own spokespersons, among others. At a press conference following her keynote address at the International Conference on AIDS held in Atlanta in 1985, then Health and Human Services secretary Margaret Heckler caused considerable consternation among people at society's margins when she implored: "We must conquer [AIDS] . . . before it affects the heterosexual population and threatens the health of our general population."[43] Her parallel statement, that we must also conquer AIDS for the sake of "individuals in every country who

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fall within the risk categories" [44] was perceived as, at best, a sop. In similar fashion, when called on to explain on a nationally telecast interview show why President Reagan did not speak publicly about AIDS until late 1985, White House chief domestic policy adviser Gary Bauer responded that until then AIDS had not been a problem worth commenting on because "it hadn't spread into the general population yet."[45]

In its weakest form, *genocide* signifies a reckless indifference to, or deliberate disregard of, the black community's vital interests, or at a minimum the subordination of those interests to the distinct concerns of the larger society. Let me illustrate by once again turning to New York City's needle-exchange program. No one, I take it, would quarrel with the proposition that the black community has a legitimate interest in discouraging its young people from using illicit drugs. Yet that very same interest is directly threatened if the fears expressed by the program's many black critics are warranted, that is to say if providing clean needles to addicts creates a substantial risk that the number of young people willing to experiment with intravenous drugs will rise significantly. The fact that the city pressed forward with the program in the face of such concerns contributed to the charge of genocide.

In fairness, it cannot be said that New York City's health commissioner simply disregarded the issue of whether free needles would encourage addiction. Rather, after thoughtfully considering the issue, he concluded that the risk was minimal.[46] The rub is that most black critics of needle exchange rejected that conclusion.[47] Given this disagreement over a matter of fundamental importance to the black community, to proceed anyway looks a lot like indifference or disrespect.

* * *

My overriding goal in writing this essay has been to spur conversation about how a country as racially polarized as ours can hope to deal with a virulent disease that, as fate would have it, manifests itself differentially. It is in the pursuit of that goal that I have struggled to give content to a charge that usually produces more heat than light. I have no particular investment in the term *genocide*; I simply want

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to jumpstart the conversation that usually dies out whenever the word is deployed.

My vision is of a conversation that takes place both on the streets and in the academy, by design and by chance. My hope is for conversation characterized by mutual risk taking and mutual candor. In the spirit of candor, I must warn you that not all will be pleasant. For most Americans of African descent, our history, especially our trials and tribulations—slavery, discrimination, malign neglect—is a lived thing, something we experience and feel even when we do not know its particulars. We wear Jim Crow like our skin, with precious little choice in the matter. Because our history is ever with us, we can never consider the slate wiped clean. It is, for example, difficult for us to divorce our dealings with white persons as individuals from our dealings with whites who preceded them. When you extend a hand in friendship, we can't help wondering whether you carry trouble in the other one. When you invite us to dinner, we can't help wondering why. If your manner of speech reflects considerable training and education, we wonder whether you are putting us down. If, instead, you speak in the vernacular, we wonder if you are being condescending. No matter how pure your motives, we will question why you are in our midst. No matter how deep your commitment, we will wonder what you are getting out of it.

My point, then, is that even as I invite you to bridge the chasm, I know it won't be easy. While we insist that you respectfully come calling, we aren't quite ready to put out the welcome mat. When you predictably bridle at our lack of hospitality, we will peer into your soul to determine whether you are simply one more white person who can't stand to see black folks asserting themselves. But even if we decide that your pique is justified (in the sense that you truly have embraced our concerns and are anxious to work with us), we will expect you to be sympathetic to our predicament while we argue that you cannot expect us to be sympathetic to yours.

Perhaps that is a lot to ask. But we as a nation must play the hand that slavery has dealt us. We cannot undo history, except through long, hard struggle. Meanwhile, we must learn to live with AIDS here and now, in the present that we find so bewildering.

In so doing, we must recognize that the face of AIDS is rapidly changing, from mostly white to predominantly black and brown. The implications of this shift for public health policy and practice are

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profound; we have just begun to explore them. But this much is clear already. As the drama unfolds, we cannot simply ask white actors to put on blackface and favor us with their best rendition of "life in de ghetto." We must increasingly turn to black actors, and to black directors and producers as well, if we are to truly capture the social meaning of the darkening epidemic. Nor can we treat as bothersome background noise black America's complex attitudes toward white America, and vice versa. Only by acknowledging such disconcerting realities do we have a prayer of a chance of escaping their constraining force.

ENDNOTES

[1]Throughout, I use the term *black community* to refer both to geographic areas in which African-Americans are concentrated and to a subculture with which African-Americans may be organically linked no matter where they reside. I trust that it will be evident from the context which of the two meanings (if not both) I intend.

[2]Unless the context suggests otherwise, I use the terms *gay community* and *white gay community* interchangeably to refer to the community of interests and support formed by gay men and lesbians who identify as such. I characterize the gay community as white because of its historical unwillingness to embrace fully its sisters and brothers of color. See, for example, Thom Beame, "Racism from a Black Perspective," in Michael J. Smith, ed., *Black Men/White Men: A Gay Anthology* (San Francisco: Gay Sunshine Press, 1983).

[3]Perhaps the best known and most comprehensive account of this early history is in Randy Shilts's *And the Band Played On* (New York: St. Martin's Press, 1987).

[4]Ibid., 540–43.

[5]See, for example, Franklyn N. Judson and Thomas M. Vernon, Jr., "The Impact of AIDS on State and Local Health Departments: Issues and a Few Answers," *American Journal of Public Health* 78 (4) (1988):387–93.

[6]Centers for Disease Control, *HIV/AIDS Surveillance Report* (Atlanta: Centers for Disease Control, March 1989).

[7]Ibid.

[8]See, for example, AIDS Surveillance Unit, *AIDS Surveillance Update* (New York: New York City Department of Health, 29 March 1989); AIDS Section, *Surveillance Report: AIDS in Connecticut* (Hartford, Conn.: State of Connecticut Department of Health Services, 31 December 1988).

[9]René Sabatier, *Blaming Others: Prejudice, Race and Worldwide AIDS* (Washington, London, Paris: The Panos Institute, 1988), 8.

[10]AIDS Surveillance Unit.

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[11]Ibid.

[12]B. Lambert, "Study Finds Antibodies for AIDS in 1 in 61 Babies in New York City," *New York Times*, 13 January 1988.

[13]S. R. Friedman et al., "The AIDS Epidemic among Blacks and Hispanics," *Milbank Quarterly* 65 (suppl. 2) (1987):477–80.

[14]Sabatier, 19; V. M. Mays and S. D. Cochran, "Acquired Immunodeficiency Syndrome and Black Americans: Special Psychosocial Issues," *Public Health Reports* 102 (2) (1987):228; and Friedman et al., 476.

[15]See generally Veneita Porter, "Minorities and HIV Infection," *New England Journal of Public Policy* 4 (1) (1988): 371. For an account of public health officials' efforts to overcome racial barriers in educating Detroit's black community about AIDS, see generally L. S. Williams, "AIDS Risk Reduction: A Community Health Education Intervention for Minority High Risk Group Members," *Health Education Quarterly* 13 (4) (1986):407–21; see also J. Kosterlitz, " 'Us,' 'Them' and AIDS," *National Journal* 20 (27) (1988):1742; and J. L. Peterson and G. Marin, "Issues in the Prevention of AIDS among Black and Hispanic Men," *American Psychologist* 43 (11) (1988):872–73.

[16] Sabatier, 134–37; E. Hammonds, "Race, Sex, AIDS: The Construction of 'Other,' " *Radical America* 20 (6) (1987):35–36.

[17]Friedman et al., 490–93; and Hammonds, 31–34.

[18]Michel Marriott, "Needle Exchange Angers Many Minorities," *New York Times*, 7 November 1988.

[19]Ibid.

[20]"Council Calls for End to Free-Needles Plan," *New York Times*, 7 December 1988.

[21]Marriott.

[22]Ibid.

[23]Ibid.

[24]Sabatier, 134–35; Friedman et al., 491. Note that this argument assumes either that black gay men do not exist or that they do not have sex with white gay men. For a multidimensional refutation of both assumptions, see Michael J. Smith. For an analysis of the silence of the white (and black) media on the racial dimension of AIDS, see Hammonds.

[25]Peterson and Marin, 872–73; Williams, 413; and Hammonds, 34–35.

[26]Kosterlitz, 1742; Mays, 227; Hammonds, 35–36; and Friedman et al., 491.

[27]See, for example, Friedman et al., 487; see also Peterson and Marin, 872–73.

[28]Bell Hooks, "Homophobia in Black Communities," *Zeta* 1 (3) (March 1988):35–38.

[29]Notable exceptions include Leonard Patterson, "At Ebenezer Baptist Church," and James S. Tinney, "Struggles of a Black Pentecostal," both in Michael J. Smith.

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[30]These include psychologists Susan D. Cochran of California State University-Northridge, Vickie M. Mays and Letitia Anne Peplau of UCLA, and Julius M. Johnson. See C. Craig and G. Harris, "Black Lesbians and Gays: Empirically Speaking," *Black/Out: The Magazine of the National Coalition for Black Lesbians and Gays* 2 (1) 1988:9.

[31]My experiences in this regard parallel those described by Bell Hooks (see note 28).

[32]Ibid.

[33]Ibid.

[34]To be sure, the words may still wound, particularly if one's "acceptance" of the terms of cruel discourse is coerced by circumstance, in particular by the felt need to remain closeted. For an interesting refutation of the old adage that "sticks and stones may break my bones, but names can never hurt me," see Richard Delgado, "Words that Wound: A Tort Action for Racial Insults, Epithets, and Name Calling," *Harv. C.R.-C.L.L. Rev.* 17 (1982):133.

[35]For moving accounts of this phenomenon, see Patterson, and Tinney (in note 29).

[36]Ibid.

[37]The risk that a black woman will be infected by a bisexual man is 4.6 times as great as for a white woman. Richard M. Selik, Kenneth G. Castro, and Marguerite Pappaioanou, "Racial/Ethnic Differences in the Risk of AIDS in the United States, *American Journal of Public Health* 78 (12) (1988):1540. To be sure, the principal means by which women in this country contract HIV is through sharing intravenous needles and "works." A distant second transmission route is sexual contact with straight male sex partners who themselves became infected via needles. Far back in third place is sexual contact with non-drug-using bisexual males. Institute of Medicine, *Confronting AIDS: Update 1988* (Washington, D.C.: National Academy Press, 1988); and William L. Heyward and James W. Curran, "The Epidemic of AIDS in the U.S.," *Scientific American* 259 (4) (1988):79.

[38]J. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: Free Press, 1981); A. M. Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Study," *Hastings Center Report* 8 (21) (December 1978).

[39]See generally Note, "Coerced Sterilization Under Federally Funded Family Planning Programs," *New England Law Review* 11 (1976):589–614.

[40]P. Reynolds, "Ex-Klan Leader Riding White Fear Toward Louisiana Legislature," *Boston Globe*, 5 February 1989.

[41]David J. Garrow, *The FBI and Martin Luther King, Jr.: From "Solo" to Memphis* (New York: W. W. Norton, 1981).

[42]Howard L. Rosenberg, *Atomic Soldiers: American Victims of Nuclear Experiments* (Boston: Beacon Press, 1980).

[43]Quoted in Sandra Panem, *The AIDS Bureaucracy* (Cambridge: Harvard University Press, 1988).

[44]Ibid.

[45]Grover, "AIDS Keywords," *October* 43 (1987):17.

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[46]Bruce Lambert, "Study Supports New York's Needle Plan," *New York Times*, 6 June 1988. See also Bruce Lambert, "Ethics and Needles," *New York Times*, 13 August 1988.

[47]A notable exception is Dr. Beny Primm, who sidesteps the issue by focusing on a different question: whether the data from other countries reliably establish that the provision of clean needles reduces the incidence of HIV infection. See M. Marriott, "Needle Exchange Angers Many Minorities," *New York Times*, 7 November 1988.

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David G. Ostrow, M.D.

AIDS Prevention through Effective Education

CHANGING THE VOLUNTARY INTERPERSONAL behaviors linked to the transmission of the HIV virus is the only "cure" for AIDS. Most HIV infections occur through sexual intercourse and the sharing of intravenous drug apparatus. In the absence of a vaccine, alerting individuals to the risk of these behaviors has become the first line of defense in preventing further HIV infection and disease.

After a regrettable delay in funding, our society is finally devoting considerable resources to educating both the general public and specific "high risk" groups about this risk. But what is the evidence that AIDS education works, and if it does, what makes it effective?

Developing effective AIDS-prevention programs must begin with an examination of the behaviors that transmit the HIV virus and the characteristics that make them difficult to change. This article is not intended as a comprehensive review of behavioral determinants in the face of AIDS, for several up-to-date reviews are available.[1] Rather, I wish to focus on several educational programs selected from my recent survey of innovative AIDS-prevention measures to control sexual behavior and intravenous drug use (see the list on page 231).

EVALUATING AIDS-PREVENTION EDUCATION

The concepts of social psychology have only recently made their way into the research on AIDS-related sexual behavior change. They have

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had the salutary effect of encouraging the study of sexual behavior change in a broad psychosocial framework. It encompasses the setting in which sexual behavior takes place, the psychological consequences of sexual behavior, and the role of relationships and of social or peer norms in determining sexual interactions. When considering sexual behavior in the complex framework of social psychology, it is important not to lose sight of our intended goal—the elimination or modification of those behaviors capable of transmitting HIV.

One particularly useful concept from social psychology is the cohort, a discrete group of individuals functioning socially and sharing certain characteristics, behaviors, likes and dislikes. Such cohorts can be narrowly defined (e.g., the office group that goes to a certain bar on Fridays after work) or broadly inclusive (e.g., the American "yuppie" of the late 1970s to mid-1980s). If we can identify a specific cohort for whom a targeted behavior is an important characteristic or "bond," we may have a useful sample for studying relevant characteristics. But in searching for the extent to which HIV-transmitting behaviors "belong to" or "are problems for" a cohort, we may stigmatize a group of individuals and suggest to outsiders that they can evade concerns about AIDS by distancing themselves from the identified cohort. Distancing has occurred repeatedly in the eight-year history of the AIDS epidemic, by both accident and design. The best-known example is the initial stereotyping of the promiscuous gay man as the high-risk group. While certainly an appropriate target for early intervention work (as the earliest cases were predominantly found in "fast track" homosexual men living in major cities with identifiable gay subcultures), this information was used by large numbers of homosexual men to deny their risk of AIDS and by sections of the heterosexual public to condemn AIDS "victims" as deserving of their fate on moral grounds.[2] At present, we are in danger of repeating history in our emphasis on the growing epidemic of HIV infection in black and Hispanic communities in major metropolitan centers. Leaders in those communities are justifiably wary of taking responsibility for HIV prevention, in part because of concerns that they will be accused of condoning homosexuality and IV drug use, activities their constituencies see as immoral or threatening to the community. The intended as well as the unintended effects of the cohort approach to

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Survey of AIDS-Prevention Programs

The innovative AIDS-prevention education projects that responded to the survey conducted for this article and the contact person at each project are as follows. A summary of each project is available from the author.

Night School
Joanne E. Mantell
Gay Men's Health Crisis, Inc.
Box 274, 132 West 24th St.
New York, N.Y. 10011

AIDS Risk-Reduction Intervention in Gay Bars
Joanne E. Mantell
Gay Men's Health Crisis, Inc.
Box 274, 132 West 24th St.
New York, N.Y. 10011

Bleachman
Les G. Pappas
Campaign Development Coordinator
San Francisco AIDS Foundation
333 Valencia
San Francisco, Calif. 94103

Project Smart
Benjamin F. Lewis
Project Director
Spectrum House
133 Oak St.
Westborough, Mass. 01581

Project Heart
(Health Education about AIDS for Residents in Treatment)
Joanne E. Mantell
Gay Men's Health Crisis, Inc.
Box 274, 132 West 24th St.
New York, N.Y. 10011

The Buddy Connection
Chuck Frutchey
Assistant Education Director
San Francisco AIDS Director
P.O. Box 6182
San Francisco, Calif. 94101-618

K.I.D.S.
(Knowing is Definitely Safer)
Bob Wood, M.D.
Education Coordinator
AIDS Prevention Project
Seattle-King County Health Department
1116 Summit
Suite 200
Seattle, Wash. 98101

AIDS prevention and evaluation must clearly be considered very carefully.

No one seems to deny, however, that certain community, ethnic, socioeconomic, and geographical differences are important to targeting AIDS educational interventions and making them effective. Interventions are frequently designed in terms of specific audiences so as to slant messages toward members of specific cohorts or community segments and provide "culturally sensitive" educational and counseling services. This procedure is both appropriate and necessary.

But the psychosocial model also tells us that simply tailoring the message to a targeted audience will not be sufficient to alter sexual or drug-use behaviors; the broader psychosocial dimensions of the cohort's behavior must also be addressed. For example, aiming AIDS-prevention messages at female minority teenagers, say through school-based pregnancy-prevention programs, will have only limited

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success unless the young women also get the social support they need to remain in high school. In turn, men in the community must be persuaded to accept "safer sex" or abstinence. Any educational program showing ignorance of widespread community beliefs or attitudes, such as religious and cultural prohibitions against condom use, can produce conflicts that nullify the intended message.

Community pressures, however, can also be channeled in a positive direction, in that the majority's adoption of behavioral change can cause the overriding or limiting of the behavioral options of individuals within a cohort. For sexual or drug-use behaviors this point is particularly pertinent, as an individual wishing to engage in "unsafe" behavior must find a willing partner. If engaging in safer sex or sterilization of drug-injection paraphernalia is widespread within the cohort, individuals are less likely to find willing partners for unsafe practices. This situation will have a twofold impact on subsequent sexual or drug-use behaviors. First, although these nonconforming individuals may initially experience frustration, they may, in fact, be educated about safe behavior by the persons they approach. Second, they will be forced to acknowledge the nonconformity of their own behavior, and the resulting ostracism may make them modify that behavior.

The compulsivity of sex and of drugs such as alcohol and cocaine as well as the abnormal functioning of the brain may all militate against the positive effects of peer prohibitions on sexual or drug-use behaviors. Regardless of the underlying mechanisms, these two compromisers of reasoning can all be seen as conditional factors that, if present, will compromise an individual's ability to control his or her behavior and substantially reduce the effects of cohort restraints. Recognition of the importance of such factors in influencing sexual behavior decision making has important implications for AIDS-prevention education.

DETERMINANTS OF BEHAVIORAL CHANGE

Knowledge of what constitutes a risky behavior for AIDS often motivates a change in behavior. This is particularly true for persons who perceive themselves as being at relatively low risk of AIDS and who are initially poorly informed about the disease and the routes of

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HIV transmission. Knowledge alone, however, is not an indicator of long-term behavior change.[3]

Knowledge

In a behavioral study of the self-reports of Chicago gay men rated relatively well-informed about AIDS, Emmons et al.[4] found level of knowledge associated with reductions in risk behavior only when the data were analyzed cross-sectionally (across the cohort at one point in time). A later longitudinal analysis of the same cohort by Joseph et al.[5], however, failed to show a significant relationship between knowledge and several behavioral outcomes. In addition, some individuals who initially adopted risk-reducing behaviors later reverted to risky practices. The authors concluded that the factors that motivate initial behavior changes may differ from those that sustain behavior changes. Becker and Joseph[6] suggested that there may be a threshold effect—a certain amount of information is necessary to initiate behavior change, but after that amount of information is attained, additional knowledge will not promote further behavior change.

The situation is even more complex when one examines the possible relationships between knowledge about AIDS and behavior or behavioral intent in less privileged populations. In more advantaged populations (e.g., gay white adult men and higher socioeconomic segments of the general population) one can consistently demonstrate positive relationships between knowledge and beliefs about personal vulnerability and behavioral change. Such relationships do not emerge in less advantaged populations (e.g., gay and runaway youth, prostitutes, inner-city minority women). In each case, there are significant environmental barriers that may interfere with the individual's ability to translate increased knowledge or acknowledgement of AIDS risk into effective behavior change. Increasing personal motivation for behavior change alone, without providing enabling assistance to overcome barriers to change, can have serious adverse consequences for mental health.

Perceived Susceptibility

The perception that one is susceptible to AIDS appears to be a better predictor of one's future behavior than knowledge about AIDS. Perception of risk may be related to individuals' views of their partners. Some gay male participants in the Chicago cohort study

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expressed confidence that they could, and did, choose safe sexual partners. This study revealed a correlation between risk perception and several measures of risk reduction.[7] Similar results have been reported among gay men in San Francisco.[8] Moreover, men who believed they had not been exposed or were harboring the virus engaged in fewer high-risk sexual practices than homosexual men who believed they had been exposed to HIV but had successfully fought off infection.[9] Perception of risk alone, however, did predict behavior change.

An AIDS-prevention education program in California high schools was found to have a significant, but disappointing, impact on risk-taking behaviors and beliefs about health.[10] Although students endorsed the behavioral health guidelines and many used condoms during intercourse, others continued to engage in high-risk behaviors. A San Francisco survey[11] showed that adolescents of ages ten through seventeen engaging in high-risk behavior (sexual intercourse, sexual intercourse with someone they did not know well, and/or unprotected intercourse) did not perceive themselves as being more likely to contact AIDS than those not engaging in those behaviors. In addition, perceptions of susceptibility were highest among white females and lowest among black males and Hispanic women, a finding that suggests educational efforts should focus on perceived susceptibility and be specific to the target population.

Perceived Severity

A study of a cohort of gay men in San Francisco found that the ability to remember a visual image of AIDS deterioration was positively related to a reduction in the number of partners in a month. Merely having a friend or an acquaintance with AIDS was not significantly related to restrictions in the number of partners per month.[12] This finding suggests that perceived severity of the disease does have an effect on subsequent behavior. In a number of gay prospective cohort studies,[13] perceived severity of the AIDS epidemic was found to be a significant predictor of both a decrease in high-risk sexual behavior and maintenance of low-risk behavior over extended periods.

Various forms of denial can reduce or minimize the threat and severity of AIDS. Osborn, for example,[14] has warned of the negative impact that premature or inflated reports of a vaccine or chemother-

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apy breakthroughs can have on mental health, behaviors, and public attitudes regarding AIDS. Indeed, among gay men, the belief that biomedical technology will provide a cure in the near future directly correlates with continuing high-risk sexual practices in both the Chicago and San Francisco cohort studies.[15]

Perceived Benefits and Costs

In addition to perceiving risk, individuals must also believe they are capable of making behavior changes and that those changes will reduce their risk. It has been recognized that the behaviors important in HIV transmission may be marked by "low changeability" because of their centrality to the self-identity and daily functioning of individuals at risk.[16] For example, McKusick and colleagues suggest that in the sexually active San Francisco gay community, individuals who have engaged in high-risk activities over many years may, in the belief that they are either already exposed or immune, see little point in changing their behavior.[17] The Chicago research group found a relationship between the perceived effectiveness of behavior change and some behavior outcomes, except in groups perceiving themselves to be at highest risk.[18] This finding may suggest that highest-risk individuals recognize behavior change as an effective means of risk reduction for others but dismiss it as too late in their own case.

Unlike other health behaviors, there is little immediate reinforcement for making behavior changes to reduce the risk of AIDS. For example, in dieting, one is able to see, feel, and have others comment on weight loss. Cleaning or not sharing needles has no immediate benefits or obvious reinforcing factors for reducing the risk of HIV transmission through sexual contact. Men who engage in high-risk sexual practices outside relationships tend to place great emphasis on sex.[19] They are also more likely to agree with negative statements regarding condom use and positive statements about the exchange of semen. Health-promoting behaviors will be adopted only if the benefits outweigh the costs. Among the costs of behavior change is the potential disruption of a long-term relationship when one partner introduces the discussion of safer sex or demands the use of condoms.

Sociodemographic Variables

Geographic factors, age, gender, race, economic status, and educational level are sociodemographic variables related to the risk of

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AIDS. Geographical location, for example, has been linked to degree of saturation of HIV positivity (the overall percent of the high-risk population that becomes infected) and the likelihood of having a close friend or lover with AIDS. Some men have reported that direct experience with someone with AIDS has motivated behavior changes.[20] Conversely, a geographic area with a low prevalence of HIV positivity (the overall percent of the high-risk population that becomes infected) can also lead to a false sense of geographic immunity. Some researchers have found that increased age and years of homosexual activity are related to persistence of high-risk activity. Prior to the recognition of AIDS, similar findings were reported for gay men at risk of hepatitis B infection suggesting that sexual behavior patterns in this group may become increasingly resistant to change over time.[21] On the other hand, researchers have found that gay-identified adolescents and young adults are at greater risk for transmission through high-risk sexual behavior,[22] perhaps because of a lack of perceived threat of the epidemic among younger persons. Since age is complicated by cohort membership, it is not surprising that the relationship between age and sexual behavior change is inconsistent across differing studies.

Because the vast majority of cohorts studied to date have been white, middle-class, well-educated men, little is known about racial and economic variables related to AIDS-risk reduction in homosexual and bisexual men. Studies of other types of health behavior change, however, have found education and income level to be positively related to the adoption of preventive health behaviors[23] and this relationship appears to hold true for HIV as well. Recent studies have indicated that when controlling for other factors (age, race, and gender), lower educational attainment and socioeconomic class are risk factors for HIV.[24] Further investigation is needed to understand differences in the factors motivating or retarding risk-reducing behavior changes in different subcultures.

Alcohol and Other Drug Use

Substance use is strongly associated with HIV-transmitting sexual behavior, including use of drugs during sex, number of drugs used, and frequency of combining drugs and sex.[25] Over half the gay men participating in the AIDS Behavioral Research Project who refrained from alcohol or other drug use during sex were likely to have been at

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no risk of infection during the previous six months, while those who used alcohol or other drugs during sex were two to three-and-a-half times more likely to engage in high-risk behaviors. Those who increased their level of risky behavior over six months were more likely to have used drugs, to have used multiple drugs, and to have had a high proportion of sexual encounters involving drugs than those who did not. A prospective cohort study of homosexual men in New York City found that the combination of recreational drug use and sexual activity was the most powerful predictor of high-risk sexual behavior.[26] Results from the Multicenter AIDS Cohort Studies (MACS) have also shown that reductions in high-risk sexual activities are significantly less likely if psychoactive substance use continues.[27] These findings are of potential importance in helping to direct AIDS-prevention efforts, especially in the light of relatively high rates of alcohol and recreational drug use in convenience samples of gay men[28] and the likelihood that intravenous drug users frequently have sexual encounters while under the influence of drugs. These data reveal that even in highly sensitized homosexual cohorts, some individuals are failing to adopt and maintain safer sex practices. The data also suggest that more attention needs to be focused on the role of alcohol and other drugs in undermining behavior change.

Social Network Affiliation and Peer Support

The decision whether to engage in a health-risk behavior is influenced by social norms in many ways. Social reinforcement is especially important for behavior changes that require cooperation and social interaction,[29] and every sexual risk situation is a social transaction. Factors such as availability or desirability of partners, emotional need for affection and contact, clarity of values, communication skills, and future relationships or family plans are all likely to influence sexual and reproductive health decisions.[30] For complete protection, risk-reduction practices must be effectively employed every time a person engages in sexual activity. Thus, decision making about health must be repeated over and over, under varying social and environmental conditions. Individuals often engage in different sexual practices, depending upon the relationship they have with their partners. Homosexual men in a primary relationship, for example, are more likely to adhere to safer sex guidelines outside their primary relationship than in their primary relationship.[31]

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Coates et al.[32] suggests that peer support has three important dimensions with respect to AIDS: general social support, peer expectations and support for social behavior, and capability of seeking help when needed. They found that loneliness and lack of social support was related to high-risk sex,[33] possibly because dissatisfaction with one's network may propel a person toward new sexual partners for closeness and support, even if it means engaging in high-risk sexual behavior. The Chicago cohort study findings suggest that while membership in a gay social-support network was not predictive of behavior change, the presence of peer norms supportive of risk reduction was consistently and positively associated with measures of sexual risk reduction over time.[34] Similarly, McKusick et al.[35] found that in adolescents, the belief that peers engage in and support low-risk sexual behaviors is a powerful predictor of this group's future behavior. Studies involving intravenous drug users are yielding similar results in promoting the use of bleach to clean syringes.[36]

Seeking help may also be related to reducing high-risk behavior. The AIDS Behavioral Research Project in San Francisco[37] found that seeking help from friends, lovers, medical personnel, clergy, and primary sex partners was associated with reduction in high-risk sexual behavior in gay men. Specific elements of peer support for safer sex practices need to be addressed in any community-based risk-reduction program. Furthermore, persons whose behavior is "closeted" (married bisexual men, for example) will be difficult to reach with educational programs aimed at communities with which these individuals have little or no identification.

Minority Issues

In the United States a disproportionate number of AIDS cases is seen among black and Hispanic individuals. Close to 80 percent of women and children with AIDS are black or Hispanic. The majority of these cases are related to IV drug use, from direct needle use, sexual contact with an IV drug user, or perinatal exposure to a mother infected through these behaviors. Black IV drug users may be at higher risk than their white counterparts, as there are indications that blacks inject drugs and share needles more often than whites.[38] Cultural factors may make sharing needles more accepted and expected among minority IV drug users, though it is also possible that new or sterile needles are simply more readily available to whites.[39]

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Blacks and Hispanics may also be at higher risk than whites because of differences in sexual behavior. There may be cultural differences in sex roles or other norms that influence communication in sexual relationships, and studies reveal racial and ethnic differences in contraceptive behavior. Black youth tend to be more sexually active than their white counterparts and to initiate sexual intercourse an average of two years earlier.[40]

Among males with AIDS whose risk factor is sexual contact, a significantly greater proportion of blacks and Hispanics have identified themselves as bisexual than have whites.[41] This situation has important ramifications for secondary transmission to women as well as for educational intervention. As stated above, closeted homosexually active men may be less inclined to consider themselves at risk, and less likely to seek out education offered for or by gay men. A recent report indicates that the neighborhoods of New York City have had a rapid shift to a higher proportion of minority gay men with AIDS, in addition to the already established high proportion of minorities among IV drug users and women with AIDS.[42] Since they may have weaker ties to an identifiable gay community than many whites, minority men who consider themselves gay are more difficult to reach through predominantly white, gay, community organizations.

Discrepancies between whites and people of color in access to care have been paralleled by discrepancies in access to AIDS-prevention interventions. Early education programs sponsored by the white community and later programs started by public agencies have usually been ill equipped and often disinclined to intervene appropriately in minority communities. In addition, the absence of significant numbers of minorities in AIDS research on knowledge, attitudes, and behavior change has made it difficult to draw conclusions about racial and ethnic differences in the determination of risk behavior and consequently about appropriate educational intervention. Both research and agencies delivering AIDS health care and educational services have an urgent need for greater involvement of minorities. Traditional methods of service delivery may prove inadequate. For services to be most effective, community members must participate in planning and assume leadership in the implementing programs.

As the caseload in minority communities becomes conspicuously higher and the myth that AIDS is a disease of white gay males is

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debunked, the level of AIDS anxiety in these communities is likely to increase. The initial reaction of many leaders in the black community has been to deny the extent of its impact. Many have attempted to distance themselves from the epidemic because of the stigma attached to its most common modes of transmission. Historically, gay activism has been muted in minority communities, and homosexuality has been less visible and less accepted than in other communities.[43] Many are also uncomfortable about perpetrating negative stereotypes based on the high percentage of minorities among IV drug cases. Interwoven with this discomfort is the fear that discrimination may snowball if race or ethnicity become any more closely associated with the AIDS epidemic.

AIDS-PREVENTION EDUCATION

While the ultimate goal of all AIDS-prevention education programs is the reduction and eventual elimination of HIV transmission, there are numerous barriers to the direct measurement of HIV transmission rates. A review of the available data on the outcomes of AIDS-prevention education programs makes it clear that most intervention programs evaluate change in terms of knowledge and attitudes, including behavioral intentions, but do not directly measure either risk behavior or HIV transmission rates.[44] Programs incorporating follow-up strategies can include before and after measures of behavior change.

Evaluation Strategies and Difficulties

Practical and ethical issues limit the value of such measurements. These issues include the difficulty of finding appropriate control groups matched in terms of risk and assessment but not participating in the interventions. Moreover, since we know the consequences of HIV infection, it may be unethical to withhold from a control group an intervention believed to be even somewhat effective. Attempts to use either historical controls or naturally occurring delays in intervention (e.g., persons on waiting lists for drug detoxification or methadone maintenance programs) pose difficulties in evaluating life-style change in a rapidly evolving set of social norms. Another problem, both technical and ethical, is the pressure on study participants to provide socially acceptable responses to survey questions

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involving sexual and drug-use behaviors in the AIDS era. Ethical problems also arise from increasing pressure to notify partners in sexually transmitted disease programs and to apply public health disease-control standards to clinicians and researchers. In undertaking evaluation methods that entail the monitoring of behaviors capable of transmitting HIV, the determination of the HIV infection status of study participants, and the inclusion of sexual or drug-use partners in the study, we can no longer hide behind the shield of absolute confidentiality of research data when we observe or evaluate cases of high HIV transmission potential.

An example of such a dilemma came from an anthropologist colleague of mine who has conducted direct observational research of needle sharing in study subjects whose HIV infection status he has known. The recently debated Proposition 102 in California included several legislative mandates, such as the elimination of anonymous HIV testing, and required reporting of all known suspected persons with HIV infection. If passed, that proposition would have drastically interfered with many AIDS-prevention education programs and their evaluation. Fine distinctions among education, research, clinical intervention, and public health interventions are increasingly blurred by the growing social concern over HIV transmission and the resulting legislation.

Given these limitations on the direct evaluation of behavior and HIV transmission rates, a number of "surrogate" evaluation methods have been developed that allow us to go beyond simply gauging AIDS knowledge and attitudes. If we know the factors that promote or prevent behavior change in a given target group, then we can measure those factors. While there is an inherent circularity to this method, it is easily applied in the natural environment of most community-based interventions, where pilot projects focusing on representative samples are used for the design and planning of broad-scale activities. An outgrowth of many such programs targeted toward the gay male community between 1981 and 1985 was a set of criteria for mounting effective community-based AIDS interventions:

Involvement of leadership from within the target community.

Use of market research and epidemiological techniques to identify appropriate messages and communication channels.

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Implementation of programs that both inform and motivate target audiences.

Focus on facilitating social and cultural change through community organizing.

Use of multiple channels of communication, including both media and face-to-face interventions.

Incorporation of broad-scale grass-roots participation in program design and implementation.

Development of centralized and easily accessible information and referral capabilities.

With these programmatic considerations and the research findings summarized above, we can formulate more specific evaluation criteria for the control of large-scale AIDS prevention education:

Is the information simple, unambiguous, and presented in a culturally sensitive fashion?

Are the behaviors to be modified specifically addressed?

Are substitute behaviors, pleasures, and social activities presented?

Are the substitute behaviors portrayed as being supported by the community? Does the message promote their widespread acceptance?

Are facilities and services available for persons needing assistance in adopting the behavior changes?

Are cultural, ethnic, economic, and geographic barriers to behavior change recognized and resources for overcoming them provided?

Are norms and values that sanction continued high-risk sexual or drug-use behaviors critically scrutinized and constructive alternatives given?

Is there follow-up to ensure that appropriate behavior change has been adopted, assess potential negative consequences, and reinforce continuance or completion of appropriate behavior change?

Programs that Work

By combining organizational content and applying outcome evaluation criteria for AIDS-prevention education programs, the elements

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of successful programs can more clearly be discerned. The following descriptions of several informative innovative programs that satisfy the above criteria are based on information provided by program directors (see endnote 1) as well as direct observation of the highlighted programs.

The STOP AIDS Program for High-Risk Gay Men: This project is one of the original San Francisco AIDS-prevention education programs created according to the principles delineated above.[45] Its success is evident in its community impact in San Francisco and in its spread to major cities throughout the United States, Canada, and Europe. It uses an effective combination of coordinated media messages and small group meetings to initiate peer norm and individual behavior change. Participants are recruited to the program through advertisement, telephone solicitation, and street outreach. Group session leaders are recruited from program participants, in a way reminiscent of community-based peer support programs for alcohol- or drug-dependent persons. In fact, much of the STOP AIDS program content appears to rely on the principles behind AA, EST, and other self-motivation and peer support interventions.

The objective of these messages and meetings is to motivate participants to reexamine their own sexual behavior while simultaneously shifting community perceptions of normative behavior. This is achieved by the group session leaders, recognizable community leaders who are themselves struggling with issues related to AIDS prevention and life-style adaptation. Particularly emphasized are examinations of feelings associated with high-risk sexual behaviors and alternative behavioral responses to those feelings. Follow-up includes the mailing of newsletters to participants, invitations to follow-up group sessions, and, if a participant is highly motivated and completely aligned with project objectives, the invitation to become a group leader or a support volunteer.

The most concrete evaluation of STOP AIDS appears in the results of yearly community telephone surveys, which indicate that the majority of gay or bisexual men in San Francisco know about the program and that as many as 20 percent have participated in it. While there are no direct data on the behavioral impact of the program, its widespread acceptance corresponds closely to the dramatic decline in unprotected anal intercourse and HIV infection

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among gay or bisexual study cohorts in San Francisco.[46] In other cities, new STOP AIDS programs are rapidly growing. Being dependent on the identification of networks for openly gay men willing to participate in self-revealing group sessions, the program may not be applicable to smaller communities or those with mostly closeted men. Relatively straightforward modifications, however, could make the program applicable to other target groups, such as prostitutes and gay teens.

Street Outreach to Intravenous Drug Users: The community-based IVDU outreach programs supported by the National Institute for Drug Abuse (NIDA) are an outgrowth of traditional ethnographic studies of the IV drug subculture and more recent AIDS outreach programs in New York City, San Francisco, and elsewhere.[47] The NIDA programs were significantly transformed, however, by the development of the "bleach and teach" method of preventing HIV transmission among IVDUs—the dispensing of small bottles of bleach for the disinfection of drug-injection apparatus and the teaching of IVDUs to use the bleach between injections. This innovation is analogous to the promoting of condoms for safer sex. Another intervention, recently introduced by the San Francisco AIDS Foundation, is a media campaign promoting "Bleachman," a comic-strip character in the form of a bleach bottle, to persuade the drug-using community to accept risk-reduction techniques. Safer drug use is not seen as the ultimate objective of the outreach programs but rather as a behavioral innovation that persons not yet able or willing to stop using drugs or to enter detoxification programs can readily adopt.

With their streetwise outreach workers and their behavior-modification strategy that is not perceived as a threat to the social organization of the IVDU community, these programs have been accepted by most communities where they have been initiated. Moreover, by avoiding the extremely controversial and politicized issue of the distribution of sterile needles, the NIDA programs have largely avoided government interference. There is remarkably little information, however, on the effectiveness of the bleach technique on HIV transmission or whether or not it promotes further behavior change, such as entering detoxification. It appears reasonable to assume that the dispensing of bleach provides a focus for further

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educational efforts. The bleach bottle itself is a tangible symbol of concern, linking the interventionist with the target network. This link can provide communication links for further educational intervention as well as opportunities for network change. The danger that as peer norm interventions are introduced, the community "leaders" (e.g., drug suppliers) will see the intervention as threatening their livelihood is ever present. To date, however, many shooting galleries and dealers have welcomed bleach intervention as a way to protect the health and ensure the patronage of their customers.

Another potential pitfall is the generation of interest in detoxification and methadone maintenance among persons unable to obtain access to such services. An innovative approach to this problem, developed by the New Jersey State drug-abuse agency, involves the distribution of vouchers facilitating access to drug detoxification programs along with educational outreach interventions.[48] This approach has been extremely successful in motivating persons to enter detoxification and may provide a critical link between the bleach-and-teach programs and the long-range objectives of detoxification and abstinence from intravenous drug use.

Obstacles to the broad application of street outreach to IVDU are both financial and political. While the distribution of bleach is not as controversial as the distribution of sterile needles, these programs have the ongoing opposition of some law enforcement agencies, who see them as encouraging drug use. Voucher systems and provision of funds for detoxification or methadone maintenance cannot expand the number of treatment slots available. The Presidential Commission on the Human Immunodeficiency Virus has recommended that such programs be rapidly expanded through a combination of increased funding and the relaxation of FDA regulations governing methadone maintenance programs. Beyond those barriers, the issues of community acceptance of drug-treatment facilities, and the provision of jobs and services to former IVDUs, remain critical determinants of the long-term success of street outreach programs.

Community-Based Interventions for High-Risk Women: Several programs aimed at providing women at high risk of HIV infection with the tools and opportunities for reducing their risk show considerable promise. In a number of cities, programs staffed by former prostitutes are providing education and condoms to women engaged

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in prostitution, both on the street and in residential facilities. As with IVDU outreach activities, the interventionists risk being perceived by the business leaders ("pimps") as threatening their livelihood, unless they are perceived as protecting their clients ("johns"). Similarly, condoms and spermicides are being promoted among African women, who are at high risk due to heterosexual transmission in areas where HIV infection among heterosexual men is endemic. Women attending sexually-transmitted-disease or general-health facilities are provided with information about AIDS, condoms, and spermicides. The high rate of adoption of these protective innovations appears to be related to both the ongoing education of women in their proper use and the willingness of their male partners to accept the innovation. Although perhaps not as effective as condoms in preventing HIV transmission, the use of spermicide suppositories, which does not require the male partner to wear a condom, appears to be more popular. Finally, school-based programs for teenage pregnancy prevention are increasingly seen as an appropriate place for AIDS education, counseling, and provision of prevention methods. The most successful of these programs combine individual counseling with communitywide education aimed at bringing men into cooperation through peer pressure. Still, there is a relative paucity of educational programs targeted to sexually active women who are not themselves IVDUs or the sexual partners of bisexual men or IVDUs.

Programs that Are Not Effective

To single out programs that are ineffective in the rapidly evolving field of AIDS-prevention education is difficult. Obviously, programs that merely provide information without the tools for implementing behavior change or motivating adoption of new peer norms will be extremely limited in effectiveness. Programs based on the distribution of leaflets or condoms without individual and media-based interventions are only introductory and cannot serve as models for effective intervention. Since media-based educational campaigns will increase demand for services and information, these must expand in tandem with the campaigns.

When specific linguistic and cultural orientations are brought to the development of educational materials, the distribution of these materials must be carefully controlled and monitored. At least one

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high-level AIDS-education program director has lost his job because of the inappropriate widespread distribution of graphic educational materials designed for gay men. The introduction of interventions inappropriate to the culture or politics of the target community, without the necessary development of community leadership support, has resulted in backlash reactions that have undermined further attempts at AIDS-prevention education. Once effective education programs are organized, the participating community leaders and organizations must have continuing education and support so that they may meet the increased demand for information and services. Counterproductive struggles over community agency funding priorities often erupt as newly enlisted organizations compete with established AIDS-education projects. For example, some persons argue that the dramatic decreases in AIDS risk behaviors demonstrated in the white, gay male cohort studies are reason to divert funds from gay community organizations to minority community organizations. Such diversion would be a very dangerous way to fund the minority AIDS-prevention efforts, as continued community support is obviously needed to extend and maintain the behavior changes already achieved by the white gay community. Additional funding for minority community efforts needs to be provided so that effective efforts in one population are not at the expense of others.

THE FUTURE OF AIDS-PREVENTION EDUCATION

AIDS-prevention education efforts will no doubt continue to grow over the next several years. By 1990, they will probably surpass even the Institute of Medicine's goal of $1 billion per year. With this rapid expansion, it is crucial that mechanisms for evaluating their effectiveness in terms of both individual behavior change and community norms be part of all AIDS-education programs. Models of behavior change and innovative techniques for evaluating the various components of these models must be improved. Within a given community, coordination and coalition building among programs at a variety of levels will become increasingly important. Development of consistent and effective messages appropriate to a particular segment of the population can be time-consuming and may appear to be irrelevant to the immediate task. Ignoring their importance, however, can lead

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to conflicts that will stymie educational programs and reduce confidence in opinion leaders.

In the United States

While the prospects for aggregate behavior change capable of interrupting the spread of the HIV epidemic in self-identified gay men are good, the outlook for heterosexual populations at risk and subgroups of gay or bisexual men and IVDUs not in treatment is less optimistic. Especially problematic, given the ultimate size of the populations at risk, is the evidence that sexually active heterosexuals, even those living in major epicenters of the AIDS epidemic, still do not take the risk of HIV infection seriously enough to be adopting safer sex practices. If indeed it takes a significant percentage of persons with AIDS from within one's own peer network to motivate behavior change, then we may see a repetition of the pattern of extensive spread of HIV before behavior change is modified. This pessimistic prediction leads to the suggestion that increased education efforts aimed at sexually active adolescents, young adults, and ethnic minority communities that do not yet see themselves as being at risk for AIDS must take high priority.

In addition, there is a need to counter arguments that transform public health issues into moral or religious issues. For example, some argue that promoting safer sex or drug-use practices encourages promiscuity and drug use. As efforts to reach minority populations expand, it will be increasingly important to avoid stigmatizing minorities or making scapegoats of particular segments of the community.

Finally, as legislation aimed at increasing AIDS prevention at the state and local levels proliferate, AIDS educators, public health officials, researchers and community leaders will have to communicate to legislators the potential for negative outcomes from shortsighted "quick fix" legislative efforts. Legislators must be persuaded that AIDS-prevention education is not an issue of civil rights against the protection of the public welfare but that both are integrally intertwined in the development of effective prevention programs. Again, the development of improved evaluation methods for ongoing and planned intervention programs will provide urgently needed data bearing on the design of useful legislation. Especially dangerous are legislative efforts that impose restrictions on the language or target

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communities of AIDS-prevention education programs. Such legislation runs counter to the principles of designing effective targeted AIDS prevention and undermines the community acceptance of broad-based prevention messages.

In Developing Countries

Many of the considerations discussed in terms of mounting large-scale AIDS-prevention education programs in the United States apply to programs in developing countries as well, with several major additional considerations. First and foremost are the severe limitations on funds and health-service delivery systems in these countries, which make mounting even the simplest of informational campaigns extremely difficult. A poignant example of this problem surfaced at the Fourth International AIDS Conference when the subject of HIV antibody testing and counseling programs arose. The health minister from a Central African nation particularly hard hit by AIDS asked how his country could provide the kind of post-test counseling and support services being recommended when they did not have any trained counselors. Furthermore, as recognized explicitly in the World Health Organization's Special Program on AIDS guidelines,[49] it may first be necessary to educate government and nongovernment leaders to recognize the importance of AIDS-prevention efforts before any resources or leadership will be provided for AIDS education. While we, as outsiders, can recognize the importance of AIDS prevention to the long-term health of developing nations, local leaders and their communities may not see AIDS as a threat equal to the more immediate problems of hunger, housing, malaria, and civil war.

Against this background, the growing success of WHO's Special Program on AIDS is remarkable. It has identified grass-roots community organizations to provide AIDS education in developing countries. The adoption of AIDS-prevention education programs in Africa, South America, and the Caribbean basin seems to be following a pattern similar to the development of programs aimed at IVDUs and other subpopulations in the United States that are difficult to reach. For example, a major collaborative AIDS-prevention education project between the Center for AIDS Prevention Studies of University of California at San Francisco and the government of Rwanda began with detailed ethnographic studies of sexual and other behaviors of women and their families. Subsequently, it was

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decided that perinatal and pediatric health stations could provide access to women at greatest risk of HIV infection and services that would assist the women in adopting and maintaining AIDS-preventive behaviors. Finally, while use of condoms was considered to be (at least theoretically) the most effective behavioral change, additional research indicates that gay men had such difficulty convincing their partners to accept condoms that companies eventually came out with spermicide-containing suppositories and foam. Ongoing research will help determine whether spermicides are as effective in such settings or populations as condoms in preventing HIV transmission, perhaps providing a new set of more culturally acceptable educational AIDS-prevention interventions.

* * *

Sensitivity to cultural, religious, and political issues in designing and implementing effective AIDS-prevention education programs is essential. These issues can be extremely subtle. For example, in some Catholic countries, AIDS educators have had difficulty promoting the concept of being "careful" in sexual relationships when the dominant religious message is to be "faithful" in relationships. Similar subtle and critical messages may lie at the heart of many controversies around AIDS prevention. As AIDS education increasingly focuses on segments of the population outside the original high-risk communities, these controversies can be expected to intensify rather than subside. Cultures that consider condoms offensive or immoral can be expected to react negatively to educational programs which, by necessity, offer condoms as an option for sexually active adolescents and young adults.

The complicated tasks of organizing dedicated coalitions of community leaders, educating them regarding AIDS, and achieving consensus on educational messages makes effective educational programs anything but easy solutions. The need to attend to infrastructure and to make the delivery of services consistent with educational messages requires an unprecedented level of cooperation of myriad community organizations and government agencies. For the naysayers who object that the targeted behavior changes are not attainable through education, the achievement of the past eight years in changing homosexual and IVDU behavior needs to be emphasized.

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If "education is the cure for AIDS" is to be more than a cliché, then we must continually seek ways to evaluate our current efforts and design educational programs which can have a maximum impact on the future AIDS epidemic. The most effective educational messages delicately balance the threat of AIDS with achievable behavioral change and thereby encourage a sense of responsibility. AIDS-prevention education is neither a black box nor a cliché, but rather an extremely difficult and necessary challenge to our society.

ENDNOTES

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